



**PARENTS & CARERS ADVOCATING FOR
THEIR DISABLED CHILDREN & THEIR FAMILIES:
OUR HUMAN RIGHTS ACT
FOR ALL THE FAMILY**

Co-produced by Parent & Carer
Alliance CIC and the British Institute
of Human Rights (December 2024)



Why we have made this guide



Parent & Carer
Alliance C.I.C.

Parent and Carer Alliance CIC is delighted to be working with the British Institute for Human Rights to create a guide for Parents and Carers to be able to advocate for their disabled children's and for their families' human rights. We are an independent, not-for-profit, Community Interest Company based in Gloucestershire established by parent carers for parent carers – everyone working at the Alliance are Parent Carers. We have lived experience of these situations, and we know how you may be feeling. We provide practical and emotional support and strive for positive change both locally and nationally. Our services include advocacy; support with Education, Health, and Care plans; payroll services for direct payments and EOTAS packages; webinars and social events. Families describe support from the Alliance:

“

The Alliance has not only helped us to gain more confidence in asking for what our child needs but have also given us a lot of understanding of how/who to ask and what we CAN ask for. When I was on my own, I felt lost, confused, and frustrated, once the Alliance started helping me, everything felt easier and things that I couldn't say, were finally heard because Alliance gave me my voice back. This saved my mental health and my families wellbeing.

We are sadly seeing a significant increase in the suffering of families we support, and we are very aware of the high level of trauma experienced by our families due to the situations that they face; some examples are included in this guide. We hope that by using this guide and supporting and educating families to empower them, families are more able to challenge the failures that they experience. We believe that this will move many situations forward so that families can get their needs met as well as raising awareness of the level of failures and the impact on families.

We understand that when you receive validation that your human rights have been breached, this could cause a negative emotional impact. Please be kind to yourself and seek support from family and friends whilst you work through any emotions that may stem from this. Seeking support and advocacy is often essential to negotiate the bureaucratic systems that parent carers face. Parent and Carer Alliance CIC contact details, along with details of organisations that can provide more support for your mental health, are listed in the [Further Information & Support Section](#) at the end of this Guide. We know how hard the injustice may impact you and your family. We want you to know that you are not alone. www.parentandcareralliance.org.uk

**The British Institute
of Human Rights**



This Guide with has been made as part of BIHR's UK Community Programme, funded by the Baring Foundation, which aims to support community groups to use Human Rights Act advocacy to tackle social injustices.

[Go to the back cover for more information about BIHR and this programme](#)

Using this Guide



This guide has been created by BIHR and the Parent & Carer Alliance to support parents and carers with children with special educational needs and disabilities. It aims to build confidence in identifying if your human rights are at risk and how to use these laws in your advocacy to secure better outcomes for your family. This Guide is in 3 parts: Duties, Rights, Action:

1

DUTIES

Part 1 is about the legal duties on public officials like local authorities to support human rights in their decision-making on SEND.

2

RIGHTS

Part 2 is about the rights in the Human Rights Act, which every child, parent and carer has. This part focuses on rights relevant to wellbeing, dignity and family.

3

ACTIONS

Part 3 is about how you can use the duties and rights in the Human Rights Act, in your parent & carer advocacy to seek better outcomes for your family members.

How human rights can help

- » Lucas's story
- » Sara's story

Who has legal duties to uphold human rights?

What are the human rights legal duties to meet people's human rights

- » Legal duty to respect, protect, and fulfil human rights
- » Legal duty to apply other laws to uphold human rights

Who has human rights?

When human rights may be risked: wellbeing & dignity

- » Real life situations

Right to non-discrimination:

What it covers & how it works

Right to private & family life,

home: What it covers & how it works

Right to be free from inhuman & degrading treatment:

What it covers & how it works

Human rights in real life

- » Intrusive assessments
- » "Not disabled enough"

Value of Human Rights Act advocacy

Human Rights Act Flowchart

- » Top Tips for the Flowchart
- » Tanya's Story using the Flowchart

Changes Checklist

Using the Human Rights Act in your advocacy

- » Steps for Advocacy Action
- » Mo's Advocacy Story
- » Initial Template Letter
- » Escalation Template Letter

Record & Review Template

Tips for Advocacy

Further Information & Support



TIPS FOR PARENT & CARER ADVOCACY

The Guide has lots of these highlighted sections with tips for parent and carer advocacy with useful information for when you are discussing your situation with officials, and trying to challenge and change decisions that impact the human rights of your child(ren) and yourself.



PART 1: DUTIES

The Human Rights Act duty on local authorities and others

How our Human Rights Act can help



The Human Rights Act helped Lucas & his family

Lucas is autistic and has Pathological Demand Avoidance and learning disabilities. He was excluded from school for hitting a teaching assistant. Although the Equality Act 2010 protects against disability discrimination, Regulations meant this did not include disabilities where people have “a tendency to physical abuse”. Lucas’s school said this meant they could exclude him.

Lucas’s family, with support, argued that Lucas has a right to education (Article 2, Protocol 1) and to non-discrimination (Article 14) under the Human Rights Act. The duty in the HRA to apply other laws in a way that supports human rights (section 2), meant that it would be discriminatory to interpret the Equality Act as allowing Lucas’s exclusion, and would disproportionately interfere with Lucas’ right to education. The school decided to let Lucas return with additional support in place to help him. This is a legal case, go to page 9 for more details.

The Human Rights Act helped Sara & her family

Sara, a young girl with learning disabilities, lived 2.8 miles from the specialist school she attended. The Local Authority (LA) policy for transport support required children to live 3 miles+ from school. Despite being unable to travel on her own, the LA said Sara would have to take 2 public buses to and from school each day. Sara’s mum Rai was distressed because Sara could not do this journey by herself, and Rai’s job, the family’s sole income, wouldn’t allow her to take Sara. An independent advocate supported Rai to challenge the decision using the Human Rights Act rights and duties. They said this blanket approach which didn’t look at Sara and Rai’s individual situations was a disproportionate interference with their right to private and family life (Article 8), especially their wellbeing, the lack of involvement in this decision, and restricting Sara’s ability to be part of her school community. The LA decided to provide Sara with transport. This is a real-life story from an advocacy group working with BIHR.



SEN laws have a range of protections and entitlements for disabled children, but it can be difficult to secure these rights. The Human Rights Act can be an additional, helpful legal tool in parent and carers’ advocacy to secure accountability at every level in the SEN journey, to get the best outcomes for children and young people.

“

Navigating the SEND system should not be a bureaucratic nightmare, difficult to navigate and requiring significant levels of legal knowledge and personal resilience. A child's access to support should not be determined by a parent's education, their social capital or the advice and support of people with whom they happen to come into contact. In some cases, parental empowerment has not happened. Children and parents are not 'in the know' and for some the law may not even appear to exist. Parents currently need a combination of special knowledge and social capital to navigate the system, and even then, are left exhausted by the experience. Those without significant personal or social capital therefore face significant disadvantage. For some, Parliament might as well not have bothered to legislate.” [Parliament's House of Commons Education Committee Report SEND \(October 2019\) paragraph 54.](#)

”

EVERYONE in the UK has all of the 16 human rights in the Human Rights Act, including children and young people with SEN and their parents, families and carers.

Human rights are the basic freedoms and protections that every person has simply because they are human. Human rights are about people being treated with dignity, respect and fairness, having a say over their lives and participating in decisions that are made about their care and treatment. Human rights provide a set of minimum standards. Our law, the Human Rights Act 1998 (HRA), guarantees these minimum standards across public services, including in health and care settings. The HRA can be a powerful advocacy tool for parents and carers because:

- ✓ It places legal duties on a range of officials (including those involved in SEN support) to apply other laws, such as the SEN legal framework in a way that supports people's human rights (section 6 HRA).
- ✓ Where there is a disagreement about which law, policy or guidance to apply, a legal duty in the HRA states all other laws etc. should be applied in a way the supports human rights (section 3 HRA).
- ✓ Where the Equality Act does not provide protection against non-discrimination the HRA's provisions can provide a safety net.
- ✓ The human rights in the HRA cover not only education, but the wider impact on a SEN child or young person's wellbeing, choice, and dignity which may be risked through inappropriate or lacking educational support and the impact on their family.
- ✓ The human rights in the HRA also belong to parents and carers.

Who has legal duties to uphold people's human rights?

The legal duties in the Human Rights Act apply to the actions, decisions, and failures to act of public authorities. **Public authorities includes "core" public authorities like Local Authorities, the NHS, state schools, etc., and other organisations that "perform a public function" which can include social care or educational support services.** These organisations and their staff are duty bearers. Examples of organisations and people who are public authorities and/or who are performing public functions in the SEN context could include:

- People who work for the local authority: EHC case workers, social workers, educational psychologists, speech and language therapists, the SEN team.
- Local Authority-run schools and their staff.
- Private specialist schools where places are funded by Local Authorities.



Throughout this guide we use the term "public official" or "decision-maker" to mean some who is a duty-bearer / has legal duties under the Human Rights Act, e.g. local authority staff or NHS staff involved in your child's life.

There has not been a specific legal case on academies being a public authority for the purposes of the Human Rights Act. There have been a number of cases where it has been accepted that they have to comply with public law generally. Public law includes the Human Rights Act.



Importantly courts and tribunals are also public authorities with legal duties under the Human Rights Act. If you have to take your case to the SEND Tribunal, you should raise your human rights concerns with them because they also have the legal duty to respect, protect, and fulfil human rights in their decision making.



TIPS FOR PARENT & CARER ADVOCACY

Staff and decision-makers across Local Authorities and the NHS, and many other services involved in your child's SEN support have a duty under the law to uphold your and your family's human rights. You can talk to them directly about human rights concerns and ask how they will address these.

What are the human rights legal duties to meet people's human rights?

The Human Rights Act works in two ways to ensure Local Authorities and other duty bearers are accountable for people's human rights:

Legal duty to respect, protect, and fulfil people's human rights in their actions, decisions, policies and practices.

Legal duty to apply and use other laws and policies to uphold human rights so far as possible.



LEGAL DUTY TO RESPECT, PROTECT, AND FULFIL PEOPLE'S HUMAN RIGHTS

The Human Rights Act means public officials have a legal duty to respect, protect and fulfil human rights in all decisions they make and actions they take (this is in section 6 of the Human Rights Act).



LEGAL DUTY TO RESPECT PEOPLE'S HUMAN RIGHTS

This means public authorities and their staff should not breach a person's human rights. This is sometimes called a negative duty because it is about not doing something, taking a step back and respecting a person's human rights. Local Authorities and other duty bearers and their staff can never make decisions which breach absolute human rights. They can only restrict non-absolute human rights if they can meet the 3 tests of: **(1) lawful + (2) legitimate aim + (3) proportionate.**

Go to in PART 2: RIGHTS to find out more about the 3 tests (page 17)



TIPS FOR PARENT & CARER ADVOCACY

Raise the respect duty with public officials when they need to stop doing something risking yours and your family's human rights. Examples could include:

- An attendance officer refraining from turning up at your home unannounced or at anti-social hours.
- An official reporting or threatening negative consequences for a certain number of school absences even though there is a good reason for them.



LEGAL DUTY TO PROTECT PEOPLE'S HUMAN RIGHTS

This means public officials must step in and take positive action to safeguard someone's human rights. This is about taking reasonable steps when there is a known and imminent risk of harm to a person's rights. This duty also applies when the public authority ought to have known about this risk, not just when they do know. This can include where the risk to a person's human rights come from another person or body, for example, a Local Authority paying a private provider for SEN support still has a duty to act even if the risk comes from the actions (or inaction) of the private provider. This is sometimes called the positive obligation or positive duty, because it is about actively taking steps.



TIPS FOR PARENT & CARER ADVOCACY

Raise this protect duty with public officials when your and your family's human rights have been risked and you need them to take reasonable steps, which are within their power, to stop that risk. Examples could include:

- Addressing the distress caused by changing a child's support package, proactively working with the child and family to understand any issues and what accommodations can be put in place.
- Recognising that a lack of care and support places a child and family at risk of serious harm, taking steps to make provisions to address that risk.



LEGAL DUTY TO FULFIL PEOPLE'S HUMAN RIGHTS

This means public officials must step in and take positive action to safeguard someone's human rights. This is about taking reasonable steps when there is a known and imminent risk of harm to a person's rights. This duty also applies when the public authority ought to have known about this risk, not just when they do know. This can include where the risk to a person's human rights come from another person or body, for example, a LA paying a private provider for SEN support still has a duty to act even if the risk comes from the actions (or inaction) of the private provider. This is sometimes called the positive obligation or positive duty, because it is about actively taking steps.



TIPS FOR PARENT & CARER ADVOCACY

Raise this fulfil duty with Local Authority staff when your and your family's human rights have been risked or breached and ask how the Local Authority will prevent this from happening again. This is even more important when the same thing happens again and again.

Examples of the fulfil duty in real life could include:

- Stopping the repeated incidents of school staff requiring a child to remove headphones, despite these being an agreed reasonable adjustment.
- A Local Authority recognising that a policy requirement to access a service which automatically stops after a certain number of sessions and then makes you reapply needs to be addressed when a child has an ongoing therapeutic need.

2

LEGAL DUTY TO APPLY OTHER LAWS AND POLICIES TO UPHOLD HUMAN RIGHTS

The Human Rights Act also means there is a legal duty on public officials to make decisions using other laws in a way that upholds people's human rights (this is in section 3 of the Human Rights Act), so far as possible. The "so far as possible" means that a public authority or its staff would have to show that another law explicitly prevents them from upholding the person's human rights. Usually, there is some discretion (or "wiggle room") which means they can do things differently.



In this guide we call this the **"human rights lens duty"** when discussing tips for parent and carer advocacy, because it is a duty to apply other laws through the lens of the Human Rights Act. This legal duty can be very powerful, because:

- ✓ It can give extra strength to your advocacy when trying to get access to a legal protection in another law, such as SEN laws.
- ✓ Not providing access to protections or rights set out in other laws is not just breaking that law but could also be a breach of human rights law.
- ✓ It provides a way to challenge "usual practices" which have been in place under other laws or policies, but which are risking human rights.
- ✓ Staff in public authorities may not know about this legal duty, so you are giving them additional legal tools to challenge decisions internally in public authorities.

This duty applies when all other laws, codes of practices, regulations, policies and guidance are being used by decision-makers. It includes the SEN legal framework, the Equality Act, and local policies, including those of the Local Authority, school, college, etc.





Lucas's family's story

Lucas's* story is shared at the start of this Guide. When he was 13, he was excluded from school because of aggressive behaviour related to unmet needs. He was not protected from disability discrimination under the Equality Act due to Regulations. However, the family went to Tribunal and argued that the Regulations should be applied in a way that supports his Human Rights Act rights to non-discrimination (Article 14) in accessing his right to education (Article 2, Protocol 1). This is about the Human Rights Act "lens" duty in section 3, to use other laws in a way that supports human rights. The Tribunal agreed and said "when [applied] in accordance with section 3 of the Human Rights Act, regulation 4(1)(c) does not apply to children in education who have a recognised condition that is more likely to result in a tendency to physical abuse."

This case means that schools and colleges must have made appropriate reasonable adjustments for disability for autistic pupils, aged under 18, before they can exclude them.

* Legal case: [C&C v Governing Body \[2018\] UKUT 269 \(AAC\)](#) names were anonymised.



TIPS FOR PARENT & CARER ADVOCACY

If a Local Authority or other public official says their policy means you cannot access SEND support and this risks your child's and/or your family's human rights, ask them to show how their policy meets the section 3 duty in the Human Rights Act to apply it in line with human rights. They may need to apply the policy differently to your situation because of the risks to your human rights, or the policy may need to change because it breaches human rights.

WHAT NEXT?

PART 1 has focused on helping you identify who has what legal duties to uphold your and your family members' human rights. Now:

Go to **PART 2:**
RIGHTS for
information
about your
human rights.

Go to **PART 3:**
ACTIONS for
information &
tools to help you
advocate for your
human rights.



PART 2: RIGHTS

Yours and your family's human rights

Who has human rights?

All 16 human rights in the Human Rights Act belong to ALL people in the UK all of the time, including children, young people, and family members.

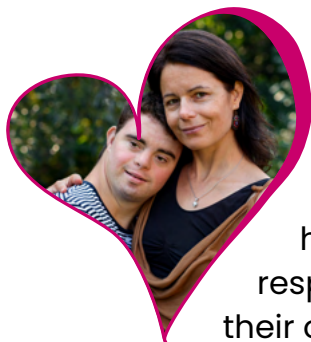
For example, all 16 of the human rights in the Human Rights Act belong to all:

- children and young people, no matter their age.
- disabled people, no matter the disability or their age.
- people with health or developmental conditions or needs (which may not be disabilities), no matter what these are.
- parents and carers, including of children and young people with SEND.



TIPS FOR PARENT & CARER ADVOCACY

You can raise concerns with the Local Authority (and other public officials, [go to Part 1 for more information](#)) about the human rights of your child AND your own human rights. Be clear whose human rights you are concerned about, but the rights apply equally to parents, family members and children.



Recognising Laura and Daniel's human rights

Laura* has multiple sclerosis, and her 13-year-old son, Daniel*, has Down's syndrome and a diagnosis of Oppositional Defiant Disorder/ Conduct Disorder. Daniel has a long history of self-harming and has attacked family members. Aside from limited respite, the family has no support to help meet Daniel's needs or their own, despite repeated requests to the Local Authority. This means Daniel has not been out of home all summer. Laura was very worried he'd seriously harm himself or a family member. With advocacy support, the family met with the Local Authority Head of Children's Services and discussed the Human Rights Act right to respect for private and family life (Article 8). They raised how this includes Daniel's right to participate in his community, but the lack of support to help meet his needs was risking this right. They also said this human right applied to Laura too and her wellbeing and participation in the life of the community was being risked. Within two weeks, Daniel's respite care was increased, he was referred to the relevant LA team for assessment and support.

Source: Voluntary sector support group accessing BIHR training. *We have changed the names.



When human rights may be risked: wellbeing and dignity

There are 16 human rights in the Human Rights Act, many of which will be relevant to your situation.* For this Guide, based on what parents and carers have told us, we have focused on 2 key human rights:

➤ **The right to be free from inhuman and degrading treatment in Article 3 of the Human Rights Act.**

➤ **The right to respect for private & family life, home & correspondence in Article 8 of the Human Rights Act.**

These human rights are about supporting wellbeing, preventing and addressing harm, involvement in decisions being made about your life and your loved one's lives, supporting families, and being able to have relationships and enjoy your community.

All human rights, including these 2 are underpinned by the **right to non-discrimination (Article 14)**.

People's physical and mental wellbeing

Significant harm to a person.



HUMAN RIGHTS IN THE HRA: SUPPORTING WELLBEING AND PROTECTING AGAINST SERIOUS HARM



RIGHT TO RESPECT FOR PRIVATE AND FAMILY LIFE

✓ Article 8.

A non-absolute human right



RIGHT TO BE FREE FROM INHUMAN OR DEGRADING TREATMENT

Article 3 ✓

An absolute human right



RIGHT TO NON-DISCRIMINATION

(Article 14, enjoying all the rights in the Human Rights Act without being discriminated against)

* You can find a [list of all 16 human rights on the back cover](#) of this Guide. BIHR has factsheets on each right on the [Get Informed Section](#) of our website.

The types of real life situations where human rights may be risked due to wellbeing and dignity concerns could include:



Harm caused by the assessment processes and interactions with the Local Authority may risk the rights to wellbeing ([Article 8](#) and [Article 14](#)), and where these cause significant trauma, pushing parents, children and family to breaking point, this may be inhuman and degrading treatment ([Article 3](#) and [Article 14](#)).



Lack of accommodations to recognise the impact of blanket approaches on disabled children and their families, e.g. refusals of health home visits when travelling to the surgery would cause a disabled child significant dysregulation, risk of flight/fright, and the associated distress this causes their parent ([Article 8](#) and [Article 14](#), and [Article 3](#) depending on the severity of distress).



A disabled child's social communication needs not being supported which means he struggles to have positive interactions with other children and can't take part in out-of-school activities like swimming lessons, clubs or play dates ([Article 8](#) and [Article 14](#)).



Denying a disabled child a wheelchair because they are able to crawl around the house ([Article 8](#) and [Article 14](#)), resulting in them being effectively unable to leave the home and the resulting distress this causes them and the family ([Article 8](#), and [Article 3](#) depending on the severity of harm).

The rest of PART 2 of this Guide looks at the right to be free from inhuman and degrading treatment ([Article 3](#)), the right to private and life ([Article 8](#)) and the right to non-discrimination ([Article 14](#)) and how these can be relevant to situations faced by SEND parents and families. However, it is important to remember there are 16 human rights in the Human Rights Act (all on the back cover of this Guide), and other ones might be important in your situation.



Find out about all 16 human rights in the [Human Rights Act on BIHR's website](#) (including **Easy Read information**). Some of the key ones which may also be relevant to your situation include:

- **The right to liberty (Article 5)**
- **The right to education (Protocol 1, Article 2)**
- **The right to peaceful enjoyment of possessions (Protocol 1, Article 1)**



THE RIGHT TO NON-DISCRIMINATION

WHAT IT COVERS AND HOW IT WORKS

This right protects you from being discriminated against when using one of the other rights in the Human Rights Act. It “piggy backs” on to the other rights because everyone should have equal access to their human rights.

Discrimination is not only being treated differently, sometimes you or your child may need a public official to do something different to make sure human rights are being supported. Unlawful discrimination under the Human Rights Act means the Local Authority is treating you:

➤ **worse than people in the same or a similar situation because of one of grounds covered by Article 14.**

For example because of your age, parental status, health status, sex, disability, language or “other status”, including age, mental capacity, homelessness, receiving a specific welfare benefit, etc.

➤ **the same as others when you are in a very different situation and need something different to uphold your human rights.**

For example, providing information about important decisions affecting your life in a format and language you can understand, which is different to the standard information usually provided.

Where a public official can show that a difference of treatment is reasonable and objectively justified it will not be discrimination. This means they have to show the differential treatment was for a very good reason. This could be for the health and safety of an individual or others, or to protect the rights of others. They still have to show how they are upholding human rights overall.



TIPS FOR PARENT & CARER ADVOCACY

When your child or your family are being treated worse than other children or families, in trying to secure education, health or care support, you can raise your rights to not be discriminated against “piggy backed” on to human rights to education (Article 2, Protocol 1), to wellbeing, choice and participation (Article 8) or when this results in serious harm (Article 3). Article 14 can also be applied when you need public officials to do something different because of “factual inequalities” experienced due to discrimination.

The non-discrimination protections in the HRA cover the Equality Act 9 protected characteristics and go wider than this, which may be useful in your situation. Discrimination grounds under the HRA which may be relevant to you, can include disability (like the Equality Act), but also health status (where this isn’t a disability), being a parent, language/communication needs.



THE RIGHT TO PRIVATE AND FAMILY LIFE, HOME AND CORRESPONDENCE

WHAT IT COVERS AND HOW IT WORKS

The right to respect to private and family life, home and correspondence (Article 8 rights) will be relevant to your life in lots of ways. An important part of this right is about public officials supporting, and not risking, people's physical and mental wellbeing, their involvement in decisions that impact their lives, and their family life and relationships.

THE RIGHT TO RESPECT FOR PRIVATE LIFE

This is about wellbeing, personal development, exercising choice, relationships with others, participation in the community, information privacy. Examples of when this might be risked could include:

Children and young people and their families experiencing distress when SEND needs are not met.

Children and young people and their families being denied the opportunity to make or keep friendships.

Children and young people not being able to develop or be part of decisions affecting them, e.g. health, care, education.

Children and young people not being supported to access their communities, e.g. in school, gaming, etc.

Parents and carers not being recognised both as carers and people in their own right.

The role of parents and carers to support and be part of decision-making about their child's life not being recognised.

Personal information which people can legitimately expect to be confidential being published or shared.

Not being able to access key personal information about oneself, including health and care records.

Experiences of bullying or harassment either by officials or if by others not addressed by them when told.

THE RIGHT TO RESPECT FOR FAMILY LIFE

This is about the ability of individuals in a family and/or the family unit to maintain family life, and keep in contact if split up. Family is not only about biological relationship, it's about close personal ties. Family can include, couples, parents and children, as well as siblings, grandparents, aunts, uncles and nieces, nephews. Examples of when this might be risked could include:

Not recognising the importance of family relationships in decision-making.

Not recognising the impact of decision-making on the family as a whole (as well as the child)

Not enabling family ties to continue to be developed when support involves residential placements.

THE RIGHT TO RESPECT FOR HOME LIFE

This is about the ability to enjoy the home a family already has (it is not a right to housing). Home is about having "sufficient and continuous links with a specific place" including houses, flats, fixed and movable homes (e.g. mobile homes and caravans). It can include a home you own, or rent, or long-term living arrangements in another's property. Examples of when this might be risked could include:

Placements which take children and young people away from their home or make them unable to enjoy it.

Moving a child or young person from a residential placement they consider home, without involving them in the change.

Significant interference by officials at the home, e.g. regular, intrusive, unannounced visits not related to risk.

THE RIGHT TO RESPECT FOR CORRESPONDENCE

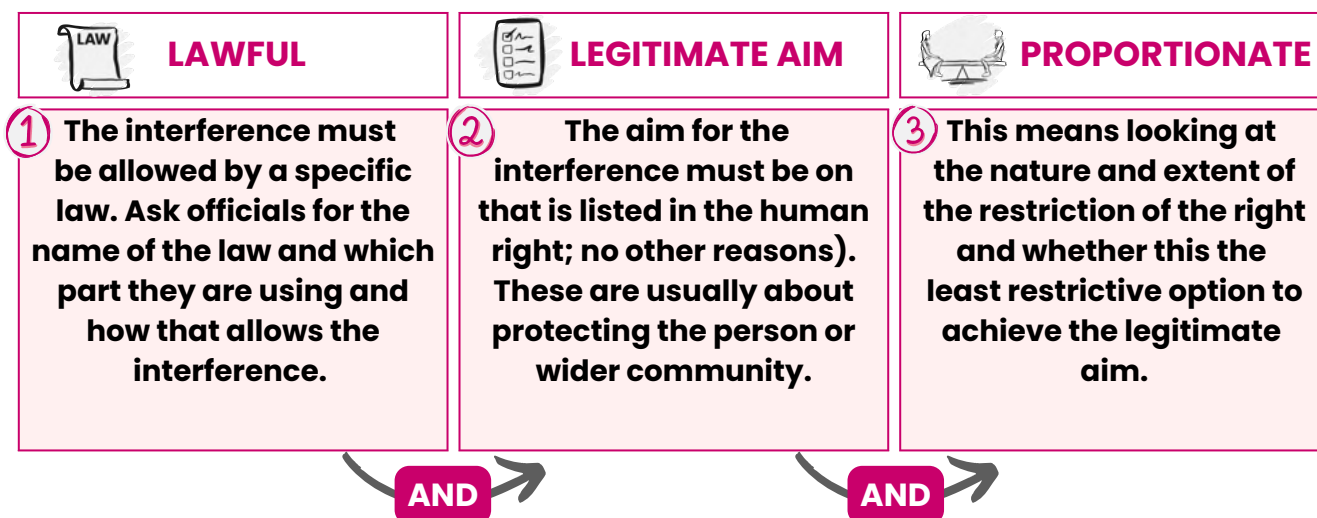
This is about the confidentiality of communications in a wide range of different situations. Correspondence means letters, and includes modern methods of communication and data, including smart phones, laptops, etc. Examples of when this might be risked could include:

Having communications with others interfered with, including via texts, letters, emails, etc.

Limited access to devices in the care of officials, e.g. blanket policies removing phones without considering impact.

THE 3 TESTS FOR LIMITING NON-ABSOLUTE HUMAN RIGHTS

The right to respect for private and family life, etc (Article 8) is a **non-absolute human right**. This means it can be interfered with by officials like Local Authorities, but only if they can pass **all of the 3-part legal tests** of the interference being:



TIPS FOR PARENT & CARER ADVOCACY

When your child or yours or your family’s wellbeing, autonomy, relationships or privacy are being put at risk by public official’s decisions, actions or failures to act, this may be risking your Article 8 rights. To interfere with (or limit) these rights the public official has to show their decision meets all of the 3 tests:

LAWFUL:

- Ask for the name of the specific law that allows the interference with rights.
- As covered in [PART 1 DUTIES](#), other laws have to be used in a way that supports people’s human rights; ask how this is being done.
- Remember, if a policy rather than a law is being relied on, the public official should not apply the policy if it breaches human rights.

LEGITIMATE AIM:

- Ask for the specific aim in Article 8 being relied on to limit your rights.
- It must be an aim written in Article 8, the official cannot choose another aim.
- Ask the decision-maker to be clear about their reasons.

PROPORTIONATE TO THAT AIM:





- Ask the official how the decision, action or failure to act is proportionate.
- Ask what alternatives were considered, and why these were not chosen.
- If you have suggestions of what could be done differently that would be less restrictive or more rights-respecting, make these and ask them why they have not been considered.



TIPS FOR PARENT & CARER ADVOCACY

If any of the 3 legal tests of lawful, legitimate aim or proportionate cannot be passed by the public official, then it is likely they are risking human rights and may even be breaching human rights, which is not allowed under the Human Rights Act. If the public official can pass all of the 3 tests, then this will likely not be risking Article 8 human rights. [Go to the Human Rights Act Advocacy Flowchart to help you decide if human rights are being risked in your situation.](#)

USING THE HUMAN RIGHTS ACT LEGAL DUTIES IN YOUR ADVOCACY WITH OFFICIALS TO ASK FOR CHANGES THAT BETTER SUPPORT YOUR HUMAN RIGHTS:

- 
RESPECT DUTY: The Article 8 rights to private and family life may be risked due to official's actions or decisions. **Ask the official to use their negative duty to take a step back and stop the interference with your human rights.**
- 
PROTECT DUTY: And/or Article 8 human rights may be risked because the official failed to step in and stop the risk to your human rights. **Ask the official to take action to protect your human rights.**
- 
FULFIL DUTY: The Article 8 rights to private and family life may already have been risked or breached and nothing has been done. **Ask the official to look at what went wrong and how to prevent further risks to your human rights.**
- 
HUMAN RIGHTS LENS DUTY: Wellbeing, choice, respect for family and other parts of the Article 8 human rights may have been risked because another law or policy has been applied in a way that has risked human rights. **Ask the official to relook at the situation using their section 3 HRA duty to apply other laws in a way that supports human rights so far as possible.**

Go to [PART 1: DUTIES](#) for a reminder of what the Human Rights Act legal duties are and which officials have these legal duties



Remember, there are groups able to support independent advocacy, including the Parent and Carer Alliance who have co-produced this Guide. For PCA's contacts and other signposting: [Further Information and Support section of this guide.](#)





THE RIGHT TO BE FREE FROM INHUMAN AND DEGRADING TREATMENT

WHAT IT COVERS AND HOW IT WORKS

The right to be free from inhuman and degrading treatment (Article 3) protects against being treated in a way that causes serious mental or physical harm or humiliation, including deliberate (abuse) and unintentional (neglect) harm.

Article 3 is an absolute human right. This means a public official can never treat you in this way. If their decision, action or failure to act risks or is inhuman and degrading treatment, they must stop and take action to remove the risk or stop breaching this human right.

Inhuman treatment or punishment

This is actual bodily injury or intense physical or mental suffering, applied hours at a time (or longer), it can be premeditated (but does not have to be).

Degrading treatment or punishment

This is treatment which humiliates or debases you, which has a lack of respect for or diminishes your dignity. It includes treatment which puts you in genuine fear or causes feelings of inferiority capable of “breaking you”* physically or emotionally. (*We explain this more in the Glossary at the end of the Guide)

Not all harm will be inhuman and degrading treatment; it must be severe, but that does consider the impact on you. There not a specific list of what is inhuman or degrading treatment, as the Human Rights Act recognises that different treatment will impact different people differently. For a Local Authority decision, action or failure to act to be inhuman or degrading you must show:



A level of serious physical or mental harm

This takes into consideration the severity of harm, how long it lasted, the effects and how long they have lasted, and whether the impact of treatment is more severe because of age, sex, disability or health status.



The specific impact of harm on you, your child or family members

This can include the purpose or motivation (if intentional treatment), but importantly it's person-centred about the effect and any vulnerabilities of those affected.

Examples of where this right to not be treated in an inhuman or degrading way might be at risk:

Disabled child in extreme distress and trauma caused by lack of appropriate health, care or education support

Inappropriate support that causes serious harm to a child or young person.

Parents and families subjected to extreme distress and trauma in navigating multiple failures of support.

Neglect or abuse by service providers who are supposed to be supporting a disabled child.

Inappropriate use of policies / procedures that have a significant damaging impact on families.

Serious bullying or harassment of a disabled child, or their parents and/or families.



TIPS FOR PARENT & CARER ADVOCACY

If a public official's decision, action or failure to act results in inhuman or degrading treatment, it will not be lawful.

If you think Article 3 rights are at risk you need to be clear explaining how, and that because it is an absolute human right the public official must address potential breaches immediately.





There may be one significant incident which results from a public official's decision, action or failure to act which amounts to inhuman or degrading treatment.

Or there may be a series of incidents which individually may be about wellbeing under Article 8, but they build up, and the totality of the harm and trauma caused amounts to inhuman or degrading treatment under Article 3.



TIPS FOR PARENT & CARER ADVOCACY

REMEMBER TREATMENT WHICH IS INHUMAN OR DEGRADING IS NEVER ALLOWED BY THE LAW NO MATTER WHY IT HAS HAPPEND. USE THE HUMAN RIGHTS LEGAL DUTIES IN YOUR ADVOCACY WITH OFFICIALS TO RAISE ARTICLE 3 CONCERNS:

- 
RESPECT DUTY: Inhuman and degrading treatment may be due to the official's actions or decisions. **Ask the official to use their negative duty to take a step back and stop the interference with your human rights.**
- 
PROTECT DUTY: And/or the inhuman or degrading treatment may be a risk because the official failed to step in and stop the risk to your human rights. **Ask the official to take action to protect your human rights.**
- 
FULFIL DUTY: Inhuman or degrading treatment may already have been risked or breached and nothing has been done. **Ask the official to look at what went wrong and how to prevent further risks to your human rights.**
- 
HUMAN RIGHTS LENS DUTY: Inhuman or degrading treatment may have happened because another law or policy has been applied in a way that has risked human rights. **Ask the official to relook at the situation using their section 3 HRA duty to apply other laws in a way that supports human rights so far as possible.**



USING HUMAN RIGHTS IN REAL LIFE: INTRUSIVE ASSESSMENT PROTOCOLS

Tony and Ellie are undergoing a Local Authority (LA) assessment for support for their disabled daughter, Lilly. The LA's protocol and process treats disabled children as "children in need" which focuses on safeguarding, child protection matters and parental 'fitness'. There are no references to assessing a child's additional support needs as a result of disability or impairment when neglect or abuse are not the reason for the referral. Tony and Ellie are finding the process intimidating and intrusive. An assessor informs them of a home visit, with less than 1 day's notice, and Tony and Ellie feel they have no option but to say yes. When the assessor arrives, she says she must see Lilly's bedroom and speak with Lilly alone, because the protocol says so. Tony and Ellie are very concerned about this, Lilly's room is her private space, where she feels safe. Lilly does not want the assessor to go in her room and she does not want to speak with the assessor, who is a stranger, alone, without her mum and dad. Tony and Ellie explain this, but the assessor says she has to follow the protocol.




USING HUMAN RIGHTS IN REAL LIFE: INTRUSIVE ASSESSMENT PROTOCOLS

continued...



Examples of how you could raise concerns with officials about this risking Article 8 human rights to respect for private and family life, and home life:

- The intrusiveness of the protocol is interfering with Tony, Ellie and Lilly’s privacy, their enjoyment of their home and is causing mental distress.
- Concerned that the 3 legal tests to interfere with this human rights have not been met because:

 LAWFUL	 LEGITIMATE AIM	 PROPORTIONATE
<p>① Safeguarding laws and policies might be the basis for inspecting the child’s room and speaking to her alone. But this is a disability needs assessment not a child protection issue.</p>	<p>② Child protection is a legitimate aim in Article 8 (protection of the person and wider community). But this is a disability needs assessment not a child protection issue.</p>	<p>③ Concern this is not a proportionate approach because it is highly restrictive and whilst there is a legitimate aim of child protection, that aim is not an issue here.</p>

- Rather than protecting Article 8 rights, this protocol and process risks breaching Article 8 rights; the LA should reconsider and ensure that a blanket approach is not applied.



Examples of how you could raise concerns with officials about this risking Article 14 human rights to non-discrimination:

- The protocol appears to be treating disabled children and their families in the same way as those whose material circumstances are materially different, i.e. those where there are safeguarding concerns.
- There also appears to be a failure to recognise the different position of disabled children and their families. Both these situations risk being discrimination under Article 14.
- Therefore, the risks to Article 8 rights are increased, as the LA’s decisions and failures to act are likely to also be discriminatory



How you could raise concerns with officials about this risking Article 3 human rights to not be treated in an inhuman or degrading way:

- The level of intrusiveness of this protocol, which is humiliating the parents, and is causing a disabled child significant distress risks breaching this human right.
- This is an absolute human right, which can never be breached, no matter the reason. Therefore the LA needs to consider if this right is being breached and take action to reduce the harm.






USING HUMAN RIGHTS IN REAL LIFE: “NOT BEING DISABLED ENOUGH”

Mimi has been trying to access support for her teenage son, Sav, who is autistic, but is finding it difficult to get an assessment of Sav’s disability related needs. Mimi has been told Sav is “not disabled enough”, and that the Local Authority team usually “deal with children with more severe disabilities”. She has been referred to Early Help but is concerned that staff do not have SEN experience. Again, she is told that they will unlikely be able to help Sav, unless or until he has a meltdown or crisis. Mimi is really worried that she has to wait until her son’s wellbeing is severely compromised before she can get him help.



Examples of how you could raise concerns with officials about this risking Article 8 human rights to respect for private and family life,:

- The lack of consideration of a disabled child’s wellbeing, requiring him to experience a crisis before accessing support, risks causing him and his mother mental distress.
- Concerned that the 3 legal tests to interfere with this human rights have not been met because:

 LAWFUL	 LEGITIMATE AIM	 PROPORTIONATE
<p>① Unsure what law is being used. Any policy being used by the Local Authority must be applied in a way that upholds human rights (section 3 HRA), but here it is negatively impacting wellbeing.</p>	<p>② Unsure what legitimate aim is. The protection of the wider community can include resource issues, but this cannot be the only consideration, the impact on the person should be considered.</p>	<p>③ Concern this is not a proportionate action. Waiting until a crisis point not only risks a disabled child’s wellbeing but will also likely lead to higher needs, with higher associated costs</p>

USING HUMAN RIGHTS IN REAL LIFE: "NOT BEING DISABLED ENOUGH"
continued...

➤ Therefore, rather than protecting Article 8 rights, this approach risks breaching Article 8 rights. The LA should reconsider and make a decision that upholds the Article 8 rights for Mimi and Sav.



Examples of how you could raise concerns with officials about this risking Article 14 human rights to non-discrimination:

➤ There appears to be a failure to recognise the different position of Sav as an autistic child, and his needs and his families.

➤ Therefore, the risks to Article 8 rights are increased, as the LA's decisions and failures to act are likely to also be discriminatory.



Examples of how you could raise concerns with officials about this risking Article 3 human rights to not be treated in an inhuman or degrading way:

➤ The continued lack of support, and time being bounced between services may lead to a significant harmful impact on a disabled child's mental health. Depending on the severity, and taking into account Sav being autistic, this could risk reaching Article 3 levels.

➤ This is an absolute human right, which can never be breached, no matter the reason. Therefore the LA needs to consider if this right is being breached and take action to reduce the harm.

WHAT NEXT?

In **PART 1: DUTIES** we looked at who has legal duties to uphold your and your family's human rights, and what those human rights are was covered in **PART 2: RIGHTS**.

Next, in **PART 3: ACTIONS** we look at how you can put this into action in your advocacy, with information, tools, real life stories & tips:

Human Rights Act Advocacy Flowchart (page 26) to help you decide if human rights are being risked, with **Top Tips** (page 29) and **Tanya's story** using the Flowchart (page 33).

Changes Checklist to help you think about what changes to ask for (page 37).

Steps for Action (page 38) and **Mo's story** (page 39) with an **Initial Template Letter** (page 44) & an **Escalation Template Letter** (page 46).



PART 3: ACTIONS


Using human rights in your advocacy


Part 3 outlines actions and tools for parents and families to use the Human Rights Act legal duties and rights in their advocacy.


The value of Human Rights Act advocacy

Sometimes other laws, like SEND law, will provide the support disabled children and their families need. However, there is often a gap between what disabled children are entitled to and what happens in reality. The impact can be that children and their families do not have their equal human dignity upheld. This is where the Human Rights Act comes in. It is an additional law which parents and families can use in their advocacy. It can be useful because:

- **It applies to all the public officials involved in SEND decision-making:** They all have the **SAME LEGAL DUTY** under the Human Rights Act to **RESPECT, PROTECT, FULFUL** the human rights of children and young people with SEND.
- **Policies, procedures and SEND laws have to be applied through a Human Rights Act lens:** The Human Rights Act is a foundation law, that means that when public officials are applying other laws (e.g. SEND law) or policies (e.g. their local policy) they have to do so in a way that uphold human rights so far as possible. This is section 3 of the Human Rights Act, and it means:
 - ✓ **If following a local policy would breach a child or young person's human rights, then the policy should not be applied.**
 - ✓ **If following Regulations or Guidance (i.e. law that is not an Act of Parliament) would breach a child or young person's human rights, then it should not be applied.**
 - ✓ **If using another law set out in an Act of Parliament (not a policy or Regulations or Guidance) they have to look at what wiggle room they have to make a different decision or apply the law differently to support someone's human rights.**

- 
Human rights provide wider context for the decision-making in SEND: This can be overlooked or not considered when making specific decisions. However, the Human Rights Act means looking at all the implications for human rights of the child or young person and their family and carers, which may be excluded from more specific laws and policies.

- 
Human rights apply to everyone in the situation – young people and family members: When focused on applying one particular law, officials can often focus only on one person in the situation. However, every person in the situation has human rights, with duties on officials to uphold.

- 
Human rights include those about being heard and part of decision-making: This means that involvement in processes, and the support needed to do so, is not a “nice to have” but is part of the law.



Remember, there are groups able to support you and help with independent advocacy, including the Parent and Carer Alliance who have co-produced this Guide. For PCA's contacts and other signposting: **[Further Information and Support section of this guide.](#)**



The Human Rights Act Flowchart: Is your issue about human rights?

The next section of this Guide provides a flowchart to help you decide if the issue(s) that are impacting your child, yourself or your family are about the Human Rights Act. If they are then you can raise your human rights with the officials, in your advocacy and discuss their legal duty to respect, protect, and fulfil human rights. We have developed this flowchart based on people's real life use of the Human Rights Act in their everyday lives.

The Human Rights Act Flowchart: Is your issue about human rights? Continued ...

BEFORE YOU USE THE FLOWCHART SOME IMPORTANT POINTS:

✔ Make sure you think about all the issues that might be risking human rights, **one situation will likely raise many human rights concerns**. Thinking about all of them will add strength to your advocacy.

✔ Also **think about all the people in the situation who are having their human rights put at risk**. For example SEND law mainly focuses on children and their support needs, which is important. The Human Rights Act is about children with support needs, but it is also about everyone else in the situation, including parents, siblings, carers and the family.

➤ **Remember you can go back and look at the stories in Part 2: RIGHTS** to see how a range of different issues might be risking human rights **and** how to think about the human rights of different people in the situation.

[Go back to Tony, Ellie and Lily's story about intrusive assessment policies \(page 21\).](#)

[Go back to Mimi and Sav's story about not being disabled enough to access support \(page 23\).](#)

✔ On the pages after the flowchart there are Top Tips for each of 7 steps in the flowchart. These are based on people's real life use of the flowchart to help you use it. **[Go to the Top Tips \(page 29\).](#)**

✔ After that we share Tanya's real life story of a lack of support for her 4 children, 3 of whom have SEND, herself and the family as a whole. We go through the flowchart to show how Tanya could show that human rights are relevant to the issues she and her children are facing. **[Go to Tanya's story \(page 33\).](#)**



The Human Rights Act Advocacy flowchart is on the next page (page 28). It is best looked at by flipping your screen or the PDF and zooming in. You can also [access the flowchart as a separate PDF document here.](#)

Human Rights Act Advocacy Flowchart

If it is not a public official making the decision, then the Human Rights Act will only apply if you alert an official who has responsibility to deal with the decision maker, e.g. the police if there is a crime, commissioners of a service, etc. If not the HRA does not apply

STEP 1: WHAT IS THE DECISION INTERFERING WITH HUMAN RIGHTS?

Is it a decision that restricts access to support? A failure to protect? A process causing distress?

Move to step 2 when you are clear about what the decision, action or failure to act is.

STEP 2: WHO MADE THE DECISION? Remember it must be a public official, e.g. staff at a Local Authority, in the NHS, etc.

Move to Step 3 if a public official(s) made the decision etc. if you're not sure go to box above.

STEP 3: WHO IS AFFECTED?

Human rights apply to the child and family members.

Move on to step 4 to decide whether the impact is about human rights

STEP 4: ARE YOUR ARTICLE 8 RIGHTS BEING AFFECTED?

Is there an interference with any of the 4 parts in the right to respect for private and family life (Article 8, Human Rights Act)?

PRIVATE LIFE

Does the decision interfere with wellbeing, exercising choice, relationships with others, participation in the community, information privacy?

FAMILY LIFE

Does the decision interfere with the ability of individuals in a family and/or family unit to maintain family life, and keep in contact if split up?

ENJOYMENT OF HOME

Does the decision effect the ability of individuals in the family and/or the family unit to enjoy the home they have together?

CORRESPONDENCE

Does the decision interfere with the ability to communicate privately with other people, whether in writing, verbally, or electronically?

YES

STEP 5: IS THE INTERFERENCE ALLOWED?

Does the official's interference pass ALL 3 of the tests to limit Article 8 rights? If any of the 3 tests are not passed, the interference with your Article 8 rights is not allowed.

(1) LAWFUL:

Is there law that allows the action, decision, etc. which is interfering with the Article 8 human rights? (Ask the official which law!)

(2) LEGITIMATE AIM:

Is there a legitimate aim as written down in Article 8 for the decision, action, etc. which is interfering with the Article 8 human rights? This is usually to protect the person or wider community. (Ask the official which aim they are trying to meet).

(3) PROPORTIONATE:

Is the decision, action, etc. which is interfering with the Article 8 human rights proportionate to the aim? (Think about whether there are other alternatives that could have been put in place that interfere less with the rights).

YES

NO

LIKELY TO BE RISKING HUMAN RIGHTS

The decision, action, etc. is likely not allowed under the Human Rights Act. Go to Changes Checklist (page 38) & Steps for Action (page 39)

UNLIKELY TO BE RISKING HUMAN RIGHTS

The decision, action, etc. is likely allowed under the Human Rights Act. If things changes do the Flowchart again to check human right issues.

YES

NO

STEP 6: REMEMBER TO ALSO CONSIDER IS DISCRIMINATION AN ISSUE?

Have you been treated worse than other people in a similar situation or are you not being treated differently when you are in a different situation to help you access your human rights? If you think it's likely that your Article 8 rights are being breached and that discrimination is an issue this makes the risk to your human rights more serious.

REMEMBER this is an absolute human right, officials are not allowed to interfere with this right and must act immediately

STEP 7: REMEMBER TO ALSO CONSIDER IS THERE INHUMAN OR DEGRADING TREATMENT?

Has a decision, action or failure to act serious impacted your dignity, causing serious physical or mental harm? This could be one big decision, action or failure to act or the build-up of lots of incidents having this impact on you. Is discrimination also an issue and adding to the harm?

YES

NO

TOP TIPS: USING THE HUMAN RIGHTS ACT FLOWCHART IN YOUR SITUATION



» STEP 1: What is the decision, action or failure?

- Note down the experience(s) you are concerned about.
- What happened, when and where?
- Is it the way someone has been treated?
- Is it a specific decision affecting someone, or a policy that applies to others?

» STEP 2: Who made it?

- **Remember the Human Rights Act duty to uphold human rights is on public bodies; so the decision, action or failure to act you are concerned about MUST have been made by a public official.** Staff working in Local Authorities and the NHS are public officials.
- Public authorities have the legal duty to respect, protect and fulfil human rights in the Human Rights Act across all their actions, decisions, etc.
- You may have been interacting with several different part of the Local Authority, be clear about which teams / departments actions are risking human rights in your situation.

Go to PART 1: DUTIES for a reminder on who has legal duties (page 6)

» STEP 3: Who is affected?

- Who is affected by the decision, action or failure? Your child(ren) with support needs will be affected, but who else is effected?
- **Remember every person has human rights, including members of the family, and you can raise risks to their human rights with the officials as part of your advocacy.** Do you have other children who are affected? Is their relationship with their sibling(s) also affected? Are you as a parent carer(s) affected? Is it affecting you individually and/or the family as a whole?
- What has been the affect? Think about the impact it has had on you, and include any relevant information about personal circumstances or characteristics (for example, age, health, disability, trauma experiences etc.) that are relevant.

TOP TIPS: USING THE HUMAN RIGHTS ACT FLOWCHART continued...



➤ STEP 4: Your Article 8 human rights to respect for private, family and home life

- This is the Article 8 human right; it is a useful starting point, because it covers many of the issues that SEND children and families will face in their interactions with public officials of all kinds, e.g. health, social care, social work, education, etc.
- This human right has 4 parts: private life; family life; enjoyment of home; and correspondence / communication with others.
- Think about each of the 4 parts: your situation might engage lots of different parts of the right, especially if you are concerned about the human rights of a range of people in the family.
- Make sure you note all this information down, and how many Article 8 human rights issues may be happening – count every issue.

Go to PART 2: RIGHTS for a reminder about what is covered by the Article 8 human rights and the Parent & Carer Advocacy Tips (page 15).

➤ STEP 5: Is the interference with Article 8 rights allowed?

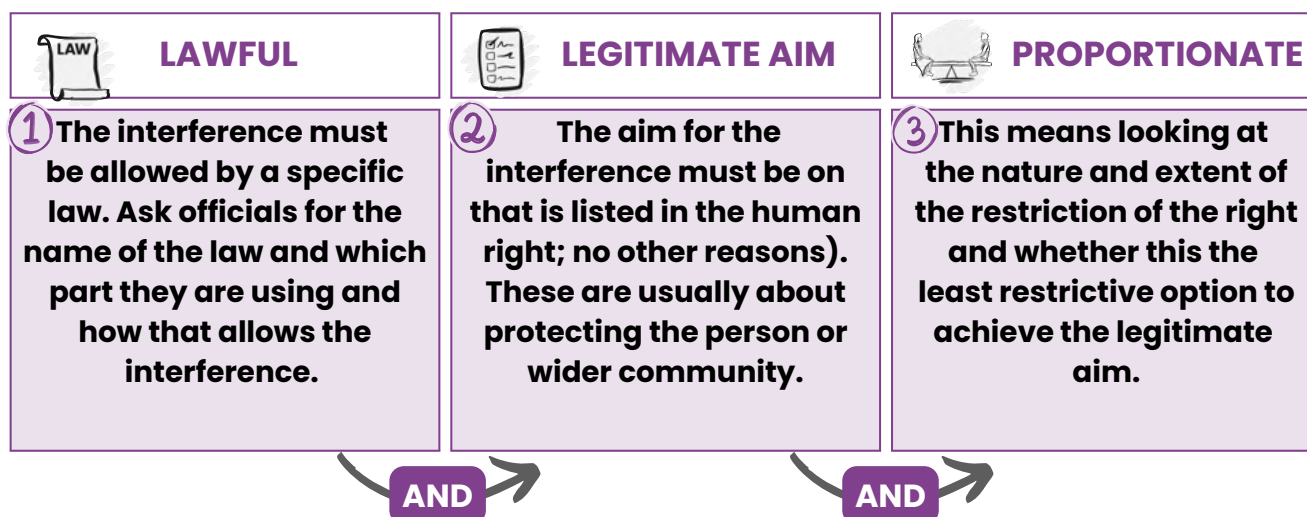
- If you think the decision, action etc. DOES NOT interfere with any of the issues in Article 8, then it is not likely to be a Human Rights Act issue.



But remember this Guide focuses only on 3 human rights (Articles 3, 8, 14), and **other human rights** in the Human Rights Act may apply. For information about all 16 human rights in the Human Rights Act, visit **BIHR's "Get Informed" website section.**

- If you think the decision, action etc. **DOES** interfere with some of the parts of the Article 8 human rights, then you need to decide **if you think the public official can show they have met all the 3 tests for interfering with the right** (these are on the next page)

TOP TIPS: USING THE HUMAN RIGHTS ACT FLOWCHART continued...



Go to PART 2: RIGHTS and the Parent & Carer Advocacy Tops on the 3 tests for restricting the Article 8 rights to private & family life (page 18).



If the public official/duty bearer DOES meet all 3 tests:

- ALL 3 of these tests need to be passed by the Local Authority/ public official to be allowed to restrict your Article 8 rights.
- **If they can then it is unlikely to be risking human rights.**
- **However, remember** that whilst some interferences may be a permitted restriction, some others may not. This is why it's important **to think about and note down ALL the possible interferences** with the Article 8 right to respect for private and family life, home and correspondence.
- Also remember to think about whether you need to consider Step 6 about discrimination and/or Step 7 about inhuman and degrading treatment.
- Even if human rights are unlikely to be risked at the moment, keep an eye on the situation, if things change, they may become human rights issues.



If the public official/duty bearer DOES NOT meet all 3 tests:

- If any of the 3 tests cannot be passed, then **the interference is likely to be risking human rights.**
- From here you need to move on to the identifying changes checklist and the action steps.
- But also remember to think whether you need to consider Step 6 about discrimination and/or Step 7 about inhuman and degrading treatment.

TOP TIPS: USING THE HUMAN RIGHTS ACT FLOWCHART continued...

**STEP 6: Is discrimination an issue?**

- Remember the right to non-discrimination in Article 14 is a piggy-back right, so it may impact your Article 8 human rights.
- Think about whether you are being treated worse than other people in a similar situation, for a particular ground or reason, e.g. due to disability, health status, parental status, carer status, etc.
- You can also think about whether the impact of treating you the same as everyone else, even though you are in a different situation, means you are worse off. For example, due to a specific health condition, the general policy about what support can be accessed means you are not getting equal access to support.
- Remember, if the public official can show a difference of treatment can be reasonably and objectively justified it will not be discrimination.

Go to PART 2: RIGHTS for a reminder of what is covered by the right to non-discrimination + the Parent and Carer Advocacy Tips (page 14)

**STEP 7: Is inhuman or degrading treatment an issue?**

- Remember this Article 3 human right is about very serious physical or mental harm that has a serious impact on your dignity.
- The legal tests are that the harm must be sufficiently serious and that it has had a serious impact on you.

Go to PART 2: RIGHTS for a reminder of what is covered by the right to be free from inhuman/degrading treatment + Parent & Carer Advocacy Tips (page 19)

- It could be about one big decision, action or failure to act by a public official decision-maker that has led to this treatment.
- Or it could be the build-up of lots of incidents having this impact on you. For example there could be a lot of Article 8 wellbeing issues that are piling up from the same public body decision-maker, or around the same situation you are experiencing. Depending on your situation, and the impact on you, this could risk being inhuman and degrading treatment.
- This is an absolute human right; that means this treatment is never allowed under the Human Rights Act so the public officials involved must act quickly to safeguard your human rights (the positive duty to step in and protect).

Next we look at Tanya's family's story and work through how to use the Human Rights Act flowchart.

TANYA'S STORY

USING THE HUMAN RIGHTS ACT FLOWCHART IN REAL LIFE SITUATIONS



Tanya, Mae, Ted, Keeley and Nate

Tanya is a single mum to 4 children, Mae, Ted, Keeley, and Nate. Mae is 12, she is close with all her siblings and regularly helps to look after them all. Ted is 10, he has been diagnosed with ADHD and moderate learning disabilities. Keeley is 4 and Nate is 2, both have been diagnosed with global development delay, both are Autistic, and incontinent. Keeley and Nate are non-verbal, with very limited understanding of language, and each uses different communication. Ted, Keeley and Nate all have very different needs. There are often conflicts between the siblings, and Mae can feel caught in the middle. Mae attends a local secondary school. Ted attends a specialist school. Keeley and Nate go to another education provider where they require 1:1 support at all times.

Tanya contacted social services for support 3 years ago, when Keeley was 1, as it was clear both she and Ted needed support; since then Nate has been born and he also has support needs. However, social services have only carried out single disability assessments (under section 17 of the Children's Act). These deal with individual disability issues, not the totality of each child's needs or the impact on the family. The assessments have not resulted in any support.

Keeley has now regularly climbed out of windows and over fences to leave the home, putting herself in danger. Tanya has had to go looking for Keeley, leaving the children unattended with Mae, also placing them at risk. Tanya made social services aware of this situation, seeking urgent assistance and support for her children. However, no additional support was provided.

This means that now when Tanya is home alone with the children, she has no option but to have all the doors and windows closed and locked, not even going into the garden. Tanya is almost never able to take the children out, because she cannot meet Ted, Keeley and Nat's high support needs, even with Mae's help.

This has been happening for the last 2 years. So when the children arrive home from school and during holidays, the family are essentially locked into the house. Tanya is also running up considerable debts trying to keep the children happy and healthy.

Tanya using the Human Rights Act Flowchart for her family

STEP 1: What is the decision, action or failure?

- » • Decision to only do single disability assessments under section 17 and failure to do a comprehensive assessment for all 3 of the disabled children – Ted, Keeley and Nate.
- Failure to provide non-school support for all 3 of the disabled children: Ted, Keeley and Nate.
- Failure to consider the needs of Tanya as a parent carer, and Mae as a young carer.

STEP 2: Who made it?

- » • Tanya has contacted the local social services social work team consistently, and whilst some section 17 assessments have been done, these are inadequate.
- Local Authority SEND team advised of the situation due to the impact on the school support arrangements, but they have not flagged internally with other teams.

STEP 3: Who does it affect?

- » • All 3 children with unmet needs, Ted, Keeley and Nate.
- Tanya as their parent and carer.
- Mae as a young sibling carer.
- Relationships between each of all the family members, conflicts between Keeley and Nate, and whole family.

STEP 4: Your Article 8 human rights to private, family home life

- » There are a range of interferences with this human right:

Wellbeing issues:

- Significant wellbeing issues for all 3 disabled children with unmet needs due to inadequate assessments.
- Impact on Mae's wellbeing as a young sibling carer.
- Significant wellbeing issues for all members of the family at being confined to the house.
- Impact on Tanya's mental health.

Exercising choice and involvement in decisions:

- Lack of involvement in decisions about care and support.
- No choices outside of school support provided, meaning all choices about leisure time are denied due to risk of Keeley leaving and lack of support the leave house.

Relationships and community

- Negative impact on ability to form and keep friendships and participate in their community outside of school for Mae, Ted, Keeley, Nate and for Tanya.
- No respite for Tanya or Mae or ability to take part in social activities outside of caring responsibilities.



Article 8
The right to respect for private
and family life, home and
correspondence

Tanya using the Human Rights Act Flowchart for her family...

STEP 4: Your Article 8 human rights to private, family home life

» Continued ...



Article 8
The right to respect for private and family life, home and correspondence

Information privacy

- Appears to be a lack of information sharing between services about the single assessments to join the dots.
- The SEND school support team, who know about the issues being able to leave the home, do not appear to have flagged this internally with colleagues to raise concerns about the impact of lack of support.

Family life

- The lack of support means the unmet needs are making relationships between siblings difficult.
- It also means the family life is very strained, with the family being confined indoors.

Enjoyment of home

- The ability to enjoy the family home is being significantly impacted by having to remain confined for safety.

STEP 5: Is the interference with these Article 8 human rights allowed?

- »
- Work through each of the issues identified as interfering with the Article 8 issues above, and decide if the 3 tests of lawful, legitimate aim and proportionate have been met or not.

Example: Applying the 3 tests to wellbeing impacts of using single disability assessments:

 **1** **LAWFUL?**
= UNLIKELY

Assessments have been done under the Children’s Act, but it does not require inadequate assessments. Social services should be looking at more appropriate alternative assessment processes. You could also ask why the Human Rights Act positive duty to protect the children’s Article 8 rights has not been addressed, as social services should know there is a risk to their wellbeing by doing the inappropriate assessments.

 **2** **LEGITIMATE AIM?**
= MAYBE

The use of a single disability assessment, taken individually, might have the legitimate aim of understanding the disability related needs of each child, whilst protecting the rights of others by considering economic resources.

 **3** **PROPORTIONATE?**
= UNLIKELY

The result of using an inadequate assessment, repeatedly, has led to significant negative impacts on each child’s Article 8 rights, and the rights of the family as a whole. The significant restrictions they’ve experienced should have been anticipated and prevented, with the more proportionate approach of using better assessments.

Tanya using the Human Rights Act Flowchart for her family...

The officials / duty bearers DO NOT meet all 3 legal tests

- • **It is likely that the Article 8 human rights to private and family life, home and correspondence, are at risk and may have been breached by the officials.**
- The next step is to move on to the Changes Checklist and the Steps for Action.
- BUT remember to also think about whether Steps 6 and 7 may be relevant first ...

STEP 6: Is discrimination an issue?

- • The standard policies of single disability assessments are being used, but the family is not in a standard position, they have 3 children with complex disabilities and support needs which are not being met.
- The family need an assessment process that can look at the complex interaction of needs.
- Without this they are receiving worse treatment on the basis of disability and health needs.
- **Likely that discrimination, against Article 14, is an issue, further affecting the family's Article 8 human rights.**



Article 14
The right to be free from discrimination

STEP 7: Is inhuman or degrading treatment an issue?

- • The family could be at risk of inhuman and degrading treatment. The lack of support has been for 2 years + and is having a significantly negative impact on each of the disabled children, as well as Mae and Tanya.
- The family has been confined to the house for long periods over several years now, significantly impacting their dignity, with no support to alleviate this despite social services teams knowing the situation.
- The impact of systemic failures and Tanya having to navigate them, may be risking her moral resistance/resilience.
- **Likely that inhuman and degrading treatment, against Article 3 in the HRA, is an issue.**



Article 3
The right to be free from torture and inhuman or degrading treatment

WHAT NEXT?

Using the Flowchart Tanya believes her children's & family's human rights to private & family life are at risk, worsened by discrimination and the risk of inhuman or degrading treatment which is never lawful under Article 3. To take action to use human rights in advocacy:

Changes Checklist to help you think about what changes to ask for (page 37).

Steps for Action (page 38) & **Mo's story** (page 39) with an **Initial Template Letter** (page 44) & **Escalation Template Letter** (page 46)

Changes Checklist



Once you have decided which human rights may be at risk, it's important to consider what changes you want to see be made by the public officials / duty-bearers involved. **Some useful things to consider:**

What is the best-case outcome you want to see?

- Is it about changing a decision, rectifying a failure to act, a policy change, etc.?
- **REMEMBER: if an absolute human right is being breached this is never lawful, and the duty-bearer must take immediate action.** SEND situations may be about the absolute human right to be free from inhuman and degrading treatment in Article 3, and possibly the right to life in Article 2 of the Human Rights Act.
- **For non-absolute human rights, like Article 8 rights to private and family life, the 3-part test of lawful, legitimate aim and proportionate needs to be passed** by the duty-bearer to restrict the right.

» **Proportionately** means the duty-bearer has looked at all the options and picked the least restrictive to achieve the legitimate aim. **Do you have alternatives to suggest which would be more proportionate?** This is a key area where changes using the Human Rights Act can be made, as you are acknowledging there may be some restriction, but you are working with the duty-bearer for a better outcome for the person(s). **Consider if you're able to accept compromises.**

What changes for which people?

- If multiple people's human rights are impacted by the risking or breaching of human rights, do you need to consider different actions / changes for different people? If so, what?

If multiple actions are needed, can you prioritise your asks?

- What needs to be done, by who and by when? Are some more urgent?
- **REMEMBER: if an absolute human right is being breached this is never lawful, and the official's with human rights duties must take immediate action.** In SEND situations this may be about the absolute human right to be free from inhuman and degrading treatment in Article 3, and possibly the right to life in Article 2 of the Human Rights Act.

Using the Human Rights Act in your Advocacy



STEPS FOR ADVOCACY ACTION

1

ESTABLISH FACTS & ANALYSE WHICH HUMAN RIGHTS MAY BE AT RISK

Ensure you have completed the Human Rights Act Flowchart to work out whether human rights and duties are an issue in your situation.



REMEMBER: If the absolute rights are at risk (e.g. freedom from inhuman treatment (Article 3) or right to life (Article 2)) raise your concerns immediately. E.g. contact safeguarding leads

2

RAISE THE ISSUE INFORMALLY WITH THE OFFICIALS MAKING THE DECISION

Request a meeting with the staff member or their manager to discuss the human rights concerns and how to address them.



If they accept human rights are at risk, work with the staff member to resolve the issue, setting out the changes you would like to see and what proportionate response can be put in place. Record and Review what is agreed, go back if there are delays.

3

RAISE THE ISSUE FORMALLY IN WRITING

If you cannot resolve the issue informally, ask for the complaints process and complain formally. Public officials must provide you with a written response and what they will do.



If they now accept human rights are at risk, as above work with the staff member to resolve the issue, agree, record and review actions. Has timing had a cumulative impact making the human rights issues more serious and urgent?

4

ESCALATE YOUR ACTION

If you cannot resolve the issue, strengthen the human rights arguments in a follow up letter, asking for an immediate meeting to discuss the response. Include a warning that you may have to take more serious action if not addressed. Write directly to the next layer of management. Copy in anyone noted in the complaint's procedure.



If they now accept human rights are at risk, as above work with the staff member to resolve the issue, agree, record and review actions. Has timing had a cumulative impact making the human rights issues more serious and urgent?

5

TAKE FURTHER ACTION

If you cannot resolve the issues, consider taking formal action involving outside agencies, suggestions across the page.



Ombudsman: Local Government & Social Care or Parliamentary & Health Services. CQC or other relevant regulator. Seek legal advice. Consider if the issue should go to the SEND Tribunal



Remember, there are groups able to support you and help with independent advocacy, including the Parent and Carer Alliance who have co-produced this Guide.

For PCA's contacts and other signposting:
[Further Information and Support section of this guide.](#)



MO'S STORY

USING THE STEPS FOR ADVOCACY ACTION IN REAL LIFE SITUATIONS



Mo, Al and Sami

Mo's son Al is 15 years old, and her daughter Sami is 11. Both are autistic and have learning disabilities, and a range of specific needs. Both are EOTAS (Education Otherwise Than At School), meaning the Local Authority agrees it would be inappropriate for any SEN provision to be delivered in a school. However, no provision has been put in place.

Al has Avoidant/Restrictive Food Intake Disorder (ARFID). He has been recently discharged from a CAMHs Tier 4 service (inpatient) because he was deemed to be at a normal weight. However, Al continues to be very distressed, and his food intake is dangerously low. Mo suspects Al will be readmitted as an inpatient within the coming weeks. The Eating Disorder Service has refused support to Al, stating that they do not get involved in ARFID cases. The issue is bouncing between CAMHs and the Eating Disorder Service. Mo has sought assistance from a specialist hospital service in London, who have contacted the local services flagging the urgent nature of Al's situation. However, local services are not responding.

Given Al's involvement with inpatient services, Amanda, a Dynamic Support Keyworker is involved. Her role is to provide specialist support and work alongside the young person, family, and other agencies to avoid hospitalisation. However, Al is receiving no support for ARFID, and neither Al nor Sami are receiving any educational or care support from the Local Authority.

This is having a significant negative impact on Al and Sami, and on Mo who is having to spend large amounts of time trying to sort out the lack of joined up services across health, education and social care and the failures to act. In addition, the service commissioned by the Local Authority to carry out carers assessments has agreed that Mo needs Personal Assistant hours. However, the Local Authority have said the report was so badly written, they will not accept it.

Mo using the Steps for Advocacy Action for her family...

1

ESTABLISH FACTS & HUMAN RIGHTS RISKS CONTINUED...

Mo has used the **Human Rights Act Flowchart** to workout which human rights are at risk in her family’s situation. You can **use tables like the ones below** to help you summarise the human rights issues when using the Flowchart:

AI’s human rights



AL’S ARTICLE 8 HUMAN RIGHTS TO RESPECT FOR PRIVATE & FAMILY LIFE:

- **Wellbeing from health services:** his mental health needs are not being supported; his physical health is at significant risk.
- **Involvement in decision-making across Local Authority (LA) & health services:** AI has a Dynamic Support Keyworker, but there is a lack of involvement in decisions about the care and support he is not receiving.
- **Developing self support from LA/education services:** lack of education provision is restricting ability to develop, negatively impacting wellbeing.
- **Community, relationships and family life not recognised across LA and health services:** ability to be part of communities, to have relationships with other people and family life is negatively impacted.

Non-absolute right, which means the officials need to pass the 3 stage test for their restrictions of this right to be allowed under the Human Rights Act:

1 LAWFUL? Unlikely	2 LEGITIMATE AIM? Unlikely	3 PROPORTIONATE? Unlikely
<p>No officials have said what law allows their interferences with AI’s human rights. There is no ETOS provision, despite agreeing it is needed. The Eating Disorder Service might be using a local policy on AFRID, it’s not clear, but even if they are they need to apply it in a way that uphold human rights (Human Rights Act lens duty).</p>	<p>No officials have given reasons for the restrictions of AI’s rights, that are legitimate aims under Article 8, e.g. to protect the person or other people. The education officials have agreed in school SEN provision is inappropriate, but not provided alternative support. Eating Disorder Service officials have just said they don’t deal with ARFID.</p>	<p>Because it is unlikely there is a legitimate aim for the restrictions to AI’s human rights it is difficult to justify these restrictions as proportionate to that aim.</p>



AL’S ARTICLE 14 HUMAN RIGHT TO NON-DISCRIMINATION:

Potentially discrimination based on health and/or disability and/or age is a feature of many of the Article 8 human rights risks, as not recognising the different position of a disabled child. E.g. the refusal of the Eating Disorder Service to get involved in ARFID could impact children and young people with co-occurring mental health or developmental conditions. Also, the lack of educational provision fails to recognise the different position of a disabled child.

Lack of evidence that officials can objectively & reasonably justify treating AI differently

Continued ...

Mo using the Steps for Advocacy Action for her family...



ESTABLISH FACTS & HUMAN RIGHTS RISKS CONTINUED (AL'S RIGHTS) ...



AL'S ARTICLE 3 HUMAN RIGHTS TO BE FREE FROM INHUMAN TREATMENT:

The failure to provide support for ARFID is having both a physical and mental impact which will lead to a serious hospital admission which is not being prevented, risks tipping into Article 3 treatment. Depending on the seriousness of the physical impact of lack of nutrition and hydration this could also impact Al's right to life under Article 2 in the Human Rights Act. The potential build-up of the wellbeing issues under Article 8 impact could also risk tipping into Article 3 treatment.

This is an absolute human right any treatment which amounts to this is never lawful.

Mo's human rights



MO'S ARTICLE 8 HUMAN RIGHTS TO RESPECT FOR PRIVATE & FAMILY LIFE:

- **Wellbeing not recognised by LA and health services:** distress from the impact of poor support, continually challenging, being a parent carer.
- **Involvement in decision-making across LA& health services:** poor involvement in decisions about children's care & treatment, continually having to challenge decisions.
- **Community, relationships & family life not recognised across LA and health services:** significant impact of continually having to challenge services, impacting family life and outside of home reducing ability to work and professional development; all impacted by LA's refusal to accept carers assessment that needs a PA

Non-absolute right, which means the officials need to pass the 3 stage test for their restrictions of this right to be allowed under the Human Rights Act:

① LAWFUL? Unlikely	② LEGITIMATE AIM? Unlikely	③ PROPORTIONATE? Unlikely
Limited justifications for some of the restrictions, e.g. officials have not said what law requires Mo to not be involved in decisions about her children. A policy may be being used for the carer's assessment, which still needs to be applied in a way that uphold human rights (Human Rights Act lens duty).	Limited justifications for some of the restrictions, e.g. officials have not said why Mo is being excluded from decision making. There is some recognition of the impact on Mo because a carer's assessment referral has been made.	For some issues, e.g. the lack of involvement in decisions there is no legitimate aim from officials, so actions are unlikely proportionate to that aim. The carers assessment referral is a proportionate step to respond to Mo's needs. But the refusal to accept it because the service have poorly written is likely disproportionate. The LA could accept the report findings and deal with the service separately.

Continued ...

Mo using the Steps for Advocacy Action for her family...

1

ESTABLISH FACTS & HUMAN RIGHTS RISKS CONTINUED (MO'S RIGHTS)...



MO'S ARTICLE 14 HUMAN RIGHT TO NON-DISCRIMINATION:

Potentially discrimination based on parent-carer status and refusal to accept carers assessment on the need for PA support.

Lack of evidence that officials can objectively & reasonably justify treating AI differently



MO'S ARTICLE 3 HUMAN RIGHTS TO BE FREE FROM INHUMAN TREATMENT:

The build-up of failures to provide support for disabled children and continually challenging this plus the LA refusal to provide assessed PA support, the distress caused by fear of serious harm to AI; **these have an overall impact of pushing Mo to breaking point, and tipping into Article 3 treatment**

This is an absolute human right any treatment which amounts to this is never lawful.

Sami's human rights



SAMI'S ARTICLE 8 HUMAN RIGHTS TO RESPECT FOR PRIVATE & FAMILY LIFE:

- **Wellbeing not recognised by LA and health services:** lack of education provision restricting ability to develop and negative impact on wellbeing.
- **Involvement in decision-making across Local Authority LA and health services:** not being involved in decisions own support.
- **Community, relationships and family life not recognised across LA and health services:** ability to be part of communities, to have relationships with other people and family life all negatively impacted.

Non-absolute right, which means the officials need to pass the 3 stage test for their restrictions of this right to be allowed under the Human Rights Act:

① LAWFUL? Unlikely	② LEGITIMATE AIM? Unlikely	③ PROPORTIONATE? Unlikely
Same as for AI and Mo above.	Same as for AI and Mo above	Same as for AI and Mo above



SAMI'S ARTICLE 14 HUMAN RIGHT TO NON-DISCRIMINATION:

Potentially discrimination based on health and/or disability and/or age is a feature of many of the Article 8 human rights risks, as not recognising the different position of a disabled child.

Lack of evidence that officials can objectively & reasonably justify treating AI differently

Continued ...

Mo using the Steps for Advocacy Action for her family...

2

RAISE THE ISSUE INFORMALLY WITH THE OFFICIALS MAKING THE DECISION

- Mo speaks to Amanda, the Dynamic Support Keyworker, sharing her concerns about the human rights which are being risked and potentially breached by lack of support for the health care and education services.
- In particular, Mo flags the risk of readmission for Al, due to lack of healthcare assistance for ARFID.
- Mo and Amanda agree the first priority is to speak with the health services – CAMHS and the Eating Disorder Service – to explain the risks involved and the potential that Al's human rights may be being risked.
- Alongside this Mo also speaks with the social services SEND support team to share her concerns that Al's, Sami's and her own human rights are at risk from the lack of support and coordination.

3

RAISE THE ISSUE FORMALLY IN WRITING

- 5 days later there has been no satisfactory response from the health services so Mo raises the issues formally, with all the relevant public officials who have Human Rights Act duties.
- Mo sets out the detail of the issues, the impact, the Human Rights Act duties and the rights at risk, and the next steps needed.
- **Mo uses the initial template letter on the next page.**
- **GENERAL TIPS:**
Include your full name and the names of the children you are advocating.
Include your full contact details, including email, telephone, and address.
Include the date you have sent the letter.
If using email you can include delivery and read receipts to confirm the email has been received and opened by the people you send it to.
It's important to keep your letter polite, to make it clear, and concise.



You can download a Word version of both the Initial Template Letter on page 45 AND the Escalation Template Letter on pages 47-49 on the Parent and Carer Alliance's website so that you can use it and change it to work for you: www.parentandcareralliance.org.uk

Continued ...

TEMPLATE LETTER FOR RAISING INITIAL HUMAN RIGHTS CONCERNS EXAMPLE: MO'S STORY

Add the names of the key people you need to contact social services, SEND team, CAMHS, etc

Dear [ADD NAMES]

Explain who you are and who you are writing on behalf of.

I am the parent advocate for Al and Samir Shah, who are both known to your services through their special educational needs and disabilities. Both children currently have unmet needs, ranging from no alternative provision as they are both EOTAS, through to serious concerns about Al's physical health due to AFIRD.

Explain the Human Rights Act duty and which human rights you think are at risk and why.

As services who should be involved the meeting the needs of my two disabled children through health, education, and care provision, you are public officials, with a duty under the Human Rights Act to respect, protect and fulfil human rights. However, the lack of provision for both children is interfering with their right to respect for private and family life (Article 8 in the Human Rights Act), by negatively impacting their wellbeing, involvement (or lack of) in decisions about their lives, and significant interference with our family life.

Explain any absolute human rights that may be at risk and the need for immediate action.

For Al in particular, he currently has no support for AFIRD, having been discharged from CAMHS inpatient care but also told the Eating Disorder Service does not treat this disorder. This raises Al's right to non-discrimination under Article 14 (HRA), as it prevents him from accessing treatment support on the basis of his disability and health-related condition. I am also concerned that his Article 3 right to free from inhuman and degrading treatment is at risk, because the refusal of support has left him in a situation of seriously declining physical health. Article 3 is an absolute human right which can never be interfered with. This means your positive obligation under the HRA to step in and take action to protect Al from such treatment is triggered. As a matter of urgency, Al needs to be able to access appropriate support for AFIRD and reduce the significant risk of harm.

Set out next steps and a timeframe to receive their response.

There are a number of other additional related matters, which also raise human rights risks that I would like to discuss. I would be grateful if you could please respond to my letter within the next 7 days so that we can resolve these issues amicably, working to protect my disabled children's human rights.

Yours sincerely
Mo Shah

Mo using the Steps for Advocacy Action for her family...

4

ESCALATE YOUR ACTION

Mo steps up the action with a more formal and detailed letter, using the Escalation Template letter on the next page, ensuring all the relevant services are copied in. To escalate the action Mo:

- Explains the human rights duties and risks in more detail.
- Starts with the absolute human right, the Article 3 right to be free from inhuman and degrading treatment, and how the absence of action is increasing the severity of risk to this right, which cannot be lawfully interfered with.
- Explains the key elements of the non-absolute Article 8 human rights issues, with more detail on each and that the 3 tests for interfering with these rights have not been met.
- Ensures the Article 14 non-discrimination rights are also highlighted specifically, with key examples.
- Sets out the urgency of immediate action and what is expect.
- Provides a copy information on the human rights being risked. You can use a table like we have used in Mo's story in Step 1, pages 41-43.
- Provides all the correspondence previously sent and any responses.
- Is clear about what further action will be taken should this not be addressed, and requests relevant further information and contacts for:
 - ➔ Complaints process and details
 - ➔ Clinical and Nursing Directors / Chiefs at the NHS Trust
 - ➔ Head of Children's Services at the Local Authority

Additional escalation measures can include:

- Requesting the Safeguarding policy and the relevant contact details.
- Requesting confirmation of the service's relevant regulator and contact information.
- Requesting contact details for the service's Board or other relevant leadership body.
- Requesting contact details for the service's commissioning body.

Remember you can download a Word version of the template letter from the Parent and Carer Alliance's website to change for your situation. Details on page 45.

Escalation template letter

To	Amanda.Grey@DynamicSupportKeyWorker.nhs.uk; manager@DynamicSupportKeyWorker.nhs.uk
Cc	R.Trevor@nhs.uk; S.Tartt@localauthority.uk; B.Shia@carerassessment.org.uk
Bcc	
Subject	Request for urgent meeting: Human rights risks in treatment and care of disabled children

Ensure the letter/email is sent to the relevant duty bearer(s), including the management.

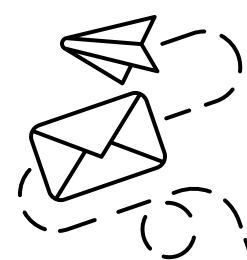
Dear Amanda, and team

As you know there have been a range of concerns around the care and treatment of my two disabled children, Al and Sami Shah, and I am receiving, and particularly Al, who is now at risk of readmission to CAMHS as an inpatient care.

Explain who you are and your relationship to the person concerned.

Speaking with you, and with the services copied into this email over the last week, I have attempted to resolve this, particular the risks to Al. Despite this and prior repeated attempts to address concerns over the last year with the various services involved, the continues to be a lack of support for both Al and Sami. Both are EOTAS, and yet not educational or care support has been put in place for over a year. Both children are highly distressed, and have had little opportunity to develop themselves, impacting wellbeing. Additionally, Al's ARFID, which the Eating Disorders Service is refusing to provide care for despite the London Hospital confirming the urgent nature of his health needs, means he is at risk of inpatient readmission, the avoidance of which is the very purpose of the Dynamic Support Keyworker programme. On top of this is the impact on myself attempting to manage this situation trying to navigate between services whose services are disconnected, resulting in further distress to my children and myself. Despite the Local Authority's commissioned carer assessment service confirming that I need PA support, the LA has refused to accept this.

Explain the background and what has happened. Introduce the impact on the person or people concerned. Ensure the most urgent situations are flagged.




Reviewing this situation, I believe that the legally protected human rights of my children, as well as myself, are now being put at serious risk by the Local Authority and NHS Services copied into this email. As I'm sure you're all aware, each of the services copied into this email have a legal duty under section 6 of the Human Rights Act 1998 (HRA) to respect, protect and fulfil our human rights. The HRA legal duties, applies across all the actions, decision, and omissions of both local authorities and NHS services. Legally, under section 2 the HRA it is the foundation for your application of all other laws and your local policies and guidance; these do not trump human rights law, and your duties under the HRA.

Explain the legal duties on the officials involved, under the Human Rights Act.




I believe there are multiple ongoing risks, and likely breaches, of several rights under the Human Rights Act. Most urgently, I believe there is a risk that AI is being treated in an inhuman and degrading way under Article 3 of the HRA. His nutrition and hydration is currently dangerously low, yet he is being refused treatment and support by the Eating Disorder Service for AFIRD, and is now at risk of inpatient readmission, but left suffering until that happens. Article 3 is an absolute human right. This means it is never legal for services to treat someone in this way, and when they are at risk of this treatment there is a positive legal duty to step in protect. All services – the Keyworker, the LA team, CAMHS and the Eating Disorder Service – copied into this email are aware of the serious risks to AI, and yet no action has been taken to support him, a disabled child, which also raises concerns about his right to non-discrimination under Article 14 in the HRA.

Set out the absolute human rights issues first because these are absolute human rights and cannot be interfered with by public officials, so immediate action needs to be taken.



Additionally, there are a significant number of risks to AI, Sami and my own Article 8 human rights to a private and family life, which need to be addressed. Attached please find a breakdown of all the human rights I believe are being put at risk by the Keyworker, the LA team, CAMHS and the Eating Disorder Service for each of us; you will see the totality of human rights risks as a result of both decisions and actions, and the failure to act. Whilst our Article 8 human rights can be limited by the services copied into this email, this can only be done if you can show each limitation meets the 3 tests of (1) lawful, (2) for a legitimate aim and (3) proportionate. I do not believe these tests have been met, for any of the instances outlined in the attached table of Article 8 human rights at risk. Rather than a law permitting the interferences with AI, Sami and my Article 8 human rights, I believe there is a failure to

Set out the non-absolute human rights issues, what they are and whether you think the 3-part test for restrictions has been met or not.



Use a table to write out the human rights issues from using the Flowchart, like in Step 1 of Mo's Story (p 42-44)

comply with the positive obligation to step in and take reasonable action to safeguard these rights. All services are currently failing to take any steps to provide appropriate care and support, failing to meet their legal duty under the Human Rights Act. As you can see from the table this is having a significant impact on each of the family member's human rights individually, and on the family as a whole, including the relationships between the siblings; all covered by Article 8.

Make sure you include the impact on each person's human rights and the impact on the family itself.

Further, I believe the right to non-discrimination under Article 14 is also being risked by the services involved. The general the lack of action to safeguard Al and Sam's Article 8 human rights appears to be related to different, i.e. worse, treatment of disabled children and their families. A specific example of discriminatory treatment is the Eating Disorders Service stating that they do get involved in ARFID cases. There also appears to be an overall lack of addressing the different position of disabled children in failing to provide educational and health support for both Al and Sami, which does not leave them worse off, and less able to access their human rights.

Set out any additional discrimination issues and why these cannot be reasonably and objectively justified.

Finally, in terms of my own human rights, given the totality of the situation I believe not only my Article 8 rights are at risk, but that this is risking my Article 3 rights. The situation and lack of support is significantly impacting my mental resistance, and the PA support I need has now been refused by the LA as they will not accept a report from the service they have commissioned. As noted above, Article 3 is an absolute human right, which means it is never lawful for services to treat people in this way.

If your human rights, as a parent or carer are also being risked, you can raise these as well.

I am therefore requesting the following actions to address the risks to the legally protected human rights of my children and myself:

- An urgent meeting, with CAMHS, SEND Support, Social Services, and the Eating Disorders Service, as all have the shared HRA legal duty to support and not breach our human rights. Given the urgency of the situation, I request a meeting be arranged with CAMHS and the Eating Disorder Services, in the next 5 days.
- As a priority we need to address the risks of inpatient readmission for Ali, the need for ongoing and preventative health support, and the wider issues about education and care support.

Explain what next steps you would like to happen and who needs to be involved. Set a specific timeframe for then you expect a response.



- A review of the ETOS support that has not been put in place for a year.
- The LA's rejection of the carer's assessment report stating that I require PA support, on the basis it is considered "badly written" needs to be revoked. The construction of the report is a matter for the LA to take up with the organisation it commissioned, not a basis on which to deny be support that puts my Article 8 rights as a parent carer, to wellbeing, at risk.

Please can you confirm receipt of this email as soon as received. I request a response within 3 days, given the urgency of the Article 3 issues outlined in this letter.

Request confirmation that your letter/ email has been received.

In your response please also provide the following information should I need to escalate urgently:

- the complaints process
- contact details for the clinical and nursing leads at the hospital
- contact details for the directors of children's services.
- the relevant regulators and ombudsman for each of the services copied into this email.

Request any information you may need to escalate the matter if it is not resolved.

Yours sincerely

Mo Shah

5

TAKE FURTHER ACTION

If the previous steps do not work, further action can include:

- Seeking support from a statutory or independent advocacy service.
- Seeking legal advice
- Contacting the relevant regulator and/or Ombudsman

[Got to Further Information and Support for signposting suggestions.](#)

Record and Review Template



It's important to keep track of what changes have been agreed, and to review actions. Turn this page on it's side, and you can fill in, copy or adapt this template in your human rights advocacy:



ISSUE	HUMAN RIGHTS CONCERN	ACTION TAKEN & BY WHO	DATE AND KEY CONTACTS	REVIEW DATE	UPDATES FOR REVIEW
E.g. Refusal to accept carers assessment report stating PA required due to report being poorly written.	E.g. Raised Article 8 concerns about wellbeing and increasing distress of having to lack of ETOAS support for children and having to challenge multiple poor decisions.	E.g. Social services team revoked refusal, accepted complaint, and processed PA request. Social services to follow up with company on reporting quality.	E.g. Acceptance of complaint by Jan Nunaton, Social Work team jan@socialworkteam.gov.uk Tel 01792 37382.	E.g. 4 weeks agreed for processing PA request. Follow up meeting 1 December 2024 at 10am.	E.g. Continued need for PA for meetings to support EOTAS discussions.

Tips for Human Rights Act Advocacy



Record the impact

Note down the impact of each decision, action or failure to act, on you and the child or young person with SEND you support. Do this at the time/as soon as possible. Notes that are kept at the time of things happening are really important evidence of what is going on.



Are other human rights relevant?

Whilst this Guide is specifically about the Article 8 human rights to private, family and home life and the Article 3 human right to be free from inhuman or degrading treatment, it's important to also think about which of the other 16 rights in the Human Rights Act may be at risk. For example, the Human Rights Act also includes the right to education, to liberty, to possessions, and in very serious cases the right to life. All 16 human rights are on the **back cover of this Guide**; you can [find out more about each of the human rights BIHR's website](#).



Are you dealing with absolute or non absolute human rights?

For each human right, think about whether they are **absolute or non-absolute**. This helps you to decide what needs to be addressed immediately because it is unlawful, and what restrictions may be allowed, but which you can negotiate for a more proportionate outcome.



Plan for the response

Think about the response you might get and plan ahead, can you suggest an alternative? Is compromise possible? What's your minimum?

Be prepared for the public officials who are duty-bearers (Local Authorities, NHS Trusts, schools, colleges, etc.) to not always fully understand their legal duties under the Human Rights Act, knowledge and implementation is patchy. Stand firm on raising human rights with them.



it's okay to use human rights language!

Don't be afraid to use human rights language, these are your human rights, and the duties of public bodies to uphold them.



Be clear that officials need to justify decisions

It is for duty-bearers to justify any restrictions they are seeking to put on people's human rights. Ask them specifically for evidence on how they have considered your and your loved one's human rights, and to explain how they are meeting their legal duties under the Human Rights Act in the situation(s) you are concerned about.



Human rights are the law

The Human Rights Act is the law, it is not a "nice to have" or an optional extra. The section 2 duty means that even if the duty-bearer is applying another law or their own policy, they must do that in a way that meets their duty to support your human rights; ask them to evidence this, in writing.



Not a battle of morals

Using human rights is **NOT** about a battle of morals, it is about recognising there is a legal framework that must be complied with and using that to work through often tricky situations. When dealing with really sensitive situations where things can become heated, it can be useful to use on the law and the language of human rights to help keep on track.



Remember, there are groups able to support you and help with independent advocacy, including the Parent and Carer Alliance who have co-produced this Guide. For PCA's contacts and other signposting: **Further Information and Support section of this guide.**



WHAT NEXT?

It may be helpful to find and access advocacy support. The Parent and Carer Alliance may be able to help you. Other charities, and organisations may be able to assist, you may want to seek legal advice, and there are several regulators who have the job of holding officials accountable.

Further Information & Support including Advice & Support + Regulators & Government Services (page 53).

Further Information & Support for emergency and non-emergency mental health issues (page 55).

Further Information and Support



Parent and Carer Alliance CIC

Parent and Carer Alliance is a not-for-profit community interest company, set up by parent carers, for parent carers. They provide independent practical and emotional support for parents and carers. They are a safe space for families to share advice, support and concerns. The Alliance works to provide information, training and events to try and help families and drives positive change.

Website: www.parentandcareralliance.org.uk

Email: info@parentandcareralliance.org.uk

Facebook: [Parent and Carer Alliance CIC](https://www.facebook.com/ParentandCarerAllianceCIC)

X (formerly Twitter): [@AndCarer](https://twitter.com/AndCarer)

BIHR

BIHR have a lot of information about the Human Rights Act and how you can use it in advocating for yourself and those you care about and for:

www.bihr.org.uk "Get Informed" section including resources, Easy Read Materials and factsheets, and our [SEND Blog Series](#).

(Note: BIHR does not provide direct advocacy, advice, or casework support).

ADVICE AND SUPPORT ORGANISATIONS

IPSEA

IPSEA is a national charity offering free and independent information, advice, support and training to make sure that children and young people with special educational needs and/or disabilities in England get the right education. They run a range of helplines: www.ipsea.org.uk

Cerebra Legal Rights Service

Cerebra's Legal Rights Service provides families of children with brain conditions with help when facing difficulties accessing support services they are entitled to. Find out more and how to make a request for help: <https://cerebra.org.uk/get-advice-support/legal-entitlements-problem-solving-project/>

AdviceUK

AdviceUK is the UK's largest support network for free, independent advice centres. They have information on where to find a range of advocacy and advice, from benefits advice to disability and health advice.

www.adviceuk.org.uk

Further Information and Support continued...

Citizens Advice Bureau

Citizens Advice provides advice in person, over the phone and via email and web chat. www.citizensadvice.org.uk



The Law Society Directory

The Law Society (England and Wales) has an online directory of law firms and solicitors. **They do not provide legal advice directly.** www.lawsociety.org.uk

Local SENDIASS

Every Local Authority has a SENDIASS (Special Educational Needs and Disabilities Information Advice and Support Service) providing free, impartial, and confidential information for young people with SEND and their parents and carers. Contact your Local Authority to find out details of your service.

REGULATORS, OMBUDSMAN AND GOVERNMENT SERVICES

Local Government and Social Care Ombudsman (LGSCO)

LGSCO looks into complaints about councils' adult social care providers (including care homes and home care agencies) and some other organisations providing local public services. www.lgo.org.uk Tel: 0300 061 0614 Mon, Tues, Thurs, Fri: 10am-1pm and Wed 1pm-4pm

Parliamentary and Health Service Ombudsman (PSHO)

PSHO looks into complaints that have not been resolved by the NHS in England and UK Government departments and other UK public organisations.

www.ombudsman.org.uk Tel: 0345 015 4033 Mon - Thurs, 8.30am to 5pm, Fri, 8.30am to 12pm

Care Quality Commission (CQC)

The Care Quality Commission is an independent organisation which makes sure health and social care services in England are providing a good service and are meeting national standards. enquiries@cqc.org.uk Tel: 03000 616161

Law Centres Network

Law Centres provide free and independent legal advice to people who cannot afford a lawyer. The network does not provide legal advice but can give contact details for your nearest centre. www.lawcentres.org.uk Tel: 020 3637 1330

Legal aid checker

Check if you're eligible for Legal Aid (support with the costs of legal advice and/or representation): www.gov.uk/check-legal-aid

You can also visit [BIHR's Get Help webpage](#) for further suggestions

Further Information and Support: Getting Mental Health Support



At the start of this Guide we said that recognising the poor treatment you and/or your loved ones have received could be breaching your human rights may impact your mental health and wellbeing. This may also come at a time when you are already feeling strained. It is important to seek help when needed.

Emergency help for mental health

If you need help for a mental health crisis, emergency or breakdown, you should get immediate expert advice and support.

You can get advice from [111 online](#) or [call 111](#) and select the mental health option. You can also contact your GP for assistance; this [NHS webpage has information on how to access support available](#).

You can also contact your local **NHS Mental Health Crisis Team** (the specific name for this team may be different in your area). You may need to be referred to this team by your GP, A & E, or the Community Mental Health Team if you are already in touch with them. 111 may also be able to put you in touch.

If there is an immediate danger to life or you are worried about yours or someone else's safety please call 999, or go to your nearest A & E Department.

PCA is based in Gloucestershire; find out more about local NHS crisis teams and other organisations who may be able to help: www.ghc.nhs.uk/crisis

Non-emergency help for mental health

- The [NHS Every Mind Matters website](#) has advice to support mental health.
- You can discuss support needs for mental health issues with your **GP**.
- You can refer yourself directly to the **NHS free talking therapies services**, [find your local service here](#). PCA is based in **Gloucestershire** where talk2gether provides talking therapy support: <https://talk2gether.nhs.uk/>
- The mental health charity **Mind** has information on ways to help yourself cope during a crisis as well as helplines: www.mind.org.uk/information-support/helplines/
- The charity the **Samaritans** provides emotional support to anyone in emotional distress, struggling to cope or at risk of suicide throughout the UK: **call (free) on 116 123** or [find out about contacting them via email, chat, letter or face to face](#).

GLOSSARY / KEY WORDS



This is a list of words that we use a lot in this Guide which explains what they mean. Some of these are about human rights law and some are related to other laws specifically about supporting children and families.

Absolute human rights

This is a human right in the Human Rights Act which a public official is never allowed to interfere with, no matter the reason (e.g. resources, staffing capacity, etc), any breach of these rights is unlawful. The two absolute human rights that tend to come up in SEND are the Article 3 right to be free from inhuman and degrading treatment covered in this guide and the Article 2 right to life.

CAMHs

This stands for Child and Adolescent Mental Health Services, the name for care provided by the NHS for children (usually to the age of 18, though some services might extend to 25) who have difficulties with their emotional well-being or mental health. Other children and young people's mental health services may be called Mental Health Support Teams (MHSTs) usually based in schools and colleges.

Disability

This is a legally defined term under the Equality Act. Someone has a disability if they have a physical or mental impairment + this has a substantial (more than minor or trivial) + long-term (lasting more than one year or likely to last more than one year) + adverse effect on their ability to carry out day-to-day activities. This is a wide definition, and can cover physical or mental health problems, and conditions such as dyslexia or autism.

Duty-bearer

This means someone (or an organisation) who has the legal duty to respect, protect, or fulfil people's human rights. In this guide we also use the term **public official**, as only those with public or governmental powers and functions have legal duties under the Human Rights Act.

Glossary / Key words continued...



Legitimate aim

Non-absolute rights can only be restricted when the restriction is for a legitimate aim (this is usually part of a 3-part test that includes the restriction being lawful and proportionate). Legitimate aims are usually about protecting the person or the wider community. Legitimate aims are either written in the text of the human right, like Article 8 for the right to respect for private and family life, or where they are not written down, they have been decided by the courts, like Article 14 for the right to non-discrimination.

Non-absolute human rights

This is a human right in the Human Rights Act which a public official may be allowed to interfere with, but only if they pass the 3 tests of the interference being (1) lawful; (2) for a legitimate aim; and (3) proportionate to achieving that aim.

Proportionate

This is a legal test for restricting non-absolute human rights. It means looking at all the options available and picking the action or making the decision that is least restrictive of the person's human rights in order to achieve the legitimate aim of the restriction.

Special educational needs (SEN)

This is a legally defined term under the Children and Families Act 2014. A child or young person may have SEN if they have a learning difficulty and/or a disability and this makes it difficult for them to use the facilities usually provided for others in mainstream school or college, or it would likely do so for children under compulsory school age.

Young person

Under the Children and Families Act, someone is a young person if they are over the compulsory school age and under 25 years old.

A note about the words "breaking you" in the tests for whether something is degrading treatment under Article 3: When deciding if treatment is degrading the Courts have used words like breaking a person's moral resistance. We have simplified this to "breaking you" and used this as "breaking point". This is about the impact of treatment someone has been subjected to, it is not about a person being mentally broken or weak.

Your notes ...



Your notes ...



THE 16 HUMAN RIGHTS WE ALL HAVE IN OUR HUMAN RIGHTS ACT:



Article 2
The right to life



Article 3
The right to be free from torture and inhuman or degrading treatment



Article 4
The right to be free from slavery and forced labour



Article 5
The right to liberty



Article 6
The right to a fair trial



Article 7
The right not to be punished for something that wasn't against the law when you did it



Article 8
The right to respect for private and family life, home and correspondence



Article 9
The right to freedom of thought, conscience and religion



Article 10
The right to freedom of expression



Article 11
The right to freedom of assembly and association



Article 12
The right to marry and start a family



Article 14
The right to be free from discrimination



Article 1, Protocol 1
The right to peaceful enjoyment of possessions



Article 2, Protocol 1
The right to education



Article 3, Protocol 1
The right to free elections



Article 1, Protocol 13
Abolition of the death penalty

About the British Institute of Human Rights:

BIHR is a UK-wide charity working to enable positive change through the practical use of our Human Rights Act, working with people, communities, public bodies, and policymakers across the UK. BIHR's UK-wide Community Programme is funded by the Baring Foundation from 2022 to 2025, and aims to strengthen the agency and voice of community and voluntary groups to address social justice issues using human rights. In this phase of the programme, BIHR partners with a small number of organisations to co-design bespoke human rights advocacy tools which will support their work with local communities.



www.bihr.org.uk



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Please scan this QR code to tell the Parent & Carer's Alliance what you think about this Guide, e.g. if it's helpful, what other human rights advocacy tools could be useful, etc. we will use this to understand impact and seek more funding to respond to further support your advocacy.

