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Human rights for young autistic people and young people with a learning disability aged 14–25

A Practitioners' Guide

The British Institute
of **Human Rights** 

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Introduction

This guide is about human rights in health and care settings. It is aimed specifically at practitioners supporting autistic people and people with a learning disability aged 14 to 25.

This guide was written by the British Institute of Human Rights in partnership with Partners in Care and Health. It aims to support you to understand your human rights duties and to place human rights at the heart of your practice. It is designed to support you in your decision making, to help you navigate difficult conversations in meetings and to assist you to work in partnership with the young people that you support.

We hope you find this guide useful in your practice.

This guide is for information purposes only. It is not intended be used as, legal advice or guidance. The law referred to in this guide is up to date at the point of publication in November 2024.



How to use this guide



The first part of this guide has introductory information about the Human Rights Act.

The second part of this guide supports you to adopt a human rights approach to decision making by introducing a human rights model and flowchart and is focused on three specific areas:



Transition from children's to adult services



Education



Care Planning

These three focus areas are looked at through a human rights lens, using real life stories to illustrate how rights-based decision-making works in practice.

Throughout this guide we link to resources for you to access more information. There is also a list of resources at the end of this guide, including links to Easy Read information about human rights.

A note about capacity and human rights:

Throughout this guide we talk about the importance of a young person being able to make decisions about their care and treatment. The right to respect for private life (Article 8) protects a person's ability to have control over their own life and to be involved in decisions about what happens to them. If a young person is aged 16 or over and they have been assessed as lacking capacity to make a specific decision, then a practitioner may make a best interests decision on their behalf (see Mental Capacity Act Code of Practice, chapter 5.8). Thinking about the person's human rights and how they might be affected should be at the centre of any decisions about best interests.

Foreword

During our work with councils and integrated care systems we often see wonderful examples of how leaders, practitioners and commissioners take action to make sure that people with a learning disability and autistic people live visible and active lives in their local communities. However, we also hear about the increasing number of people living in the community with high levels of support, with some people living with three support workers or more throughout the day and night. This can make it difficult for people to develop friendships and relationships, to see family and to do all the things that make a good fulfilling life. Additionally, we've heard that moving into adult services is especially challenging for young people with a learning disability and autistic young people.

This leaflet has been developed to highlight the importance of promoting the rights of young people with a learning disability and young autistic people. We have included some examples of where rights can be undermined alongside case studies that show the positive impact of rights-based approaches for people with a learning disability and autistic people.

We hope you will find it to be an empowering tool to enable young autistic people and young people with a learning disability to live great lives in their own homes."

Partners in Care and Health, Learning Disability and Autism Team



The Human Rights Act

What are human rights?



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.



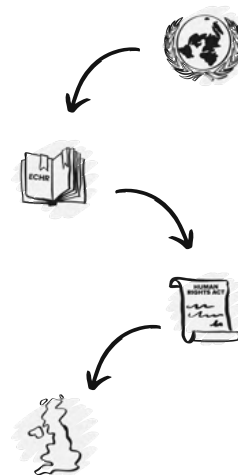
Human rights are universal, which means they are for everyone, no matter who we are. Young autistic people and young people with a learning disability have the same rights as everybody else.



Human rights provide a set of minimum standards. This idea came out of the horrors of World War II when the global community came together to set down in law rules for how governments should treat people. Our law, the Human Rights Act 1998 (HRA), guarantees these minimum standards across public services, including in health and care settings.

What is the Human Rights Act?

The Human Rights Act is the main way human rights are protected in the UK. It is an important law in the UK that protects the fundamental rights and freedoms of individuals. It takes 16 of the rights written into the **European Convention on Human Rights (ECHR)** and puts them into UK law, making them enforceable in the courts here in the UK.



Why do human rights matter to your practice?



Human rights are not 'new' or an 'add on' for public services, they are the law!

Human rights will underpin many of the situations you come across in your day-to-day work.

The Human Rights Act is designed as a framework to help negotiate better outcomes at a practice level, outside of courts. As a practitioner you can:

- Use the Human Rights Act framework as a practical tool to help inform your practice. Being able to identify the human rights involved and the impact a particular decision, policy or action will have on a young person's human rights will help you to deliver good quality care that is person-centred. This includes being able to review and change decisions internally with colleagues and in your interaction with other services.

- Work with young people, their advocates, families or carers so they to empower them to know and ask for their rights to be met and to listen and respond when they raise concerns about public bodies not respecting or protecting their rights through everyday discussions and negotiations.

How does the Human Rights Act work?

There are three things you need know about how the Human Rights Act works:



- 1.** It puts a legal duty on public bodies and their staff to respect, protect and fulfil human rights across their actions, decisions, policies, services, etc. This legal duty can be helpful for practitioners: you can use it to underpin your decisions, to challenge practice internally, and to drive positive change to deliver rights-respecting services.



2. Other laws should be applied in a way that respects people's human rights, as far as possible.



3. If 1 and 2 are not complied with, people can now bring legal cases in UK courts and tribunals (public bodies can also ask the courts to make a decision where there are disputes about the best course of action).

What are public authorities?

There are two types of bodies which have legal duties to respect, protect and fulfil human rights. We sometimes refer to these as duty-bearers.

Core public authorities are organisations you would traditionally think of as public services, i.e. government-run services. This includes NHS services, local councils, police and emergency services, as well as regulatory bodies, courts and tribunals.

There are also **hybrid or functional public bodies**. This includes private organisations, charities, or not-for-profit organisations which are delivering 'public functions'. Other factors which can indicate whether a public function is taking place, is if that function is funded by a core public authority, or if that function is regulated. This could include for example private care agencies or care homes that are providing care on behalf of a core public authority.

The legal duties can be shared, but they can't be passed along to another agency. For example, if a local authority contracts out their social housing provision to a private body, both bodies will have legal duties under the HRA.

What are the legal duties?

The legal duty on public bodies (and bodies that are delivering a public function) under the HRA has three parts.



Respect: This means ensuring you respect people's rights. Avoid interfering with someone's rights, unless it is a right you can restrict, and you have followed the correct legal process for doing this (explained later in this guide). This is sometimes called a 'negative' duty.



Protect: This requires action to safeguard people's human rights. This can include protecting a person known to be at risk of serious harm. This is sometimes called a 'positive' duty or obligation.



Fulfil: This means investigating when human rights have been breached and trying to stop it from happening again. This is sometimes called a 'procedural' duty.

How does the Human Rights Act work with other laws?



The HRA operates as a foundation law. This means that all other legislation, including health and social care law and guidance, should be compatible with human rights or 'human rights compliant' ([Section 3 HRA](#)).

The HRA is the foundation on which other laws should be built or applied (whether they were passed before or after the HRA). In practice this means the laws that are relevant to your practice such as the Mental Health Act 1983, The Mental Capacity Act 2005 and the Care Act 2014 should be implemented in a way that respects, protects and fulfils human rights.

What does this mean in practice?

- If following a local policy would breach a 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 young person's human rights, then it should not be applied. The Supreme Court said this is because the HRA is an Act of Parliament and therefore laws which are not made by Parliament which is "subordinate" law. (This also applies to policies and guidance.
- "The Human Rights Act is an act of the United Kingdom parliament and takes precedence over subordinate legislation such as the regulation in question ... This means that incompatible subordinate legislation must simply be ignored ... There is nothing unconstitutional about a public authority, court or tribunal disapplying a provision of subordinate legislation which would otherwise result in their acting incompatibly with a Convention right, where this is necessary in order to comply with the HRA. Subordinate legislation is subordinate to the requirements of an Act of Parliament. The HRA is an Act of Parliament, and its requirements are clear."
Case: R v Secretary of State for Work and Pensions (2019)

If you are using another law set out in an Act of Parliament (not a policy or Regulations or Guidance), then you will have to look at what wiggle room you have to make a different decision or apply the law differently to support someone's human rights.



Sarah's story

Sarah is a single parent of an autistic son who has been held in mental health hospitals and subjected to restrictive practices. He was put in seclusion, restrained by several members of staff and stripped naked. He couldn't see his family and was watched 24 hours a day. While the staff had powers under the Mental Health Act, it was inhuman and degrading to interpret them in this way. Sarah used Section 3 of the Human Rights Act to challenge the way the Mental Health Act was being used and the decisions made about her son's care. Her son was discharged just before his 18th birthday with a bespoke package of care and he is now living happily and independently and attending college.

What rights are in the Human Rights Act?

There are 16 rights which are protected by the HRA.



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

 = absolute rights.

 = part absolute, part non-absolute.

Absolute and non-absolute rights

Not all of our human rights work in the same way. Some of human rights are absolute, and some are non-absolute.



Absolute rights must never be restricted or interfered with under any circumstances. There is never a lawful reason for restricting someone's absolute right.



Non-absolute rights can sometimes be restricted, but you must follow a 3-part test to ensure that your decision is rights-respecting:



1. Lawful – Is there a law which allows this restriction?



2. Legitimate aim – Do you have a legitimate reason for restricting this right? Usually this is about protecting the person whose rights are being restricted from harm, or protecting other people from harm.



3. Proportionate – Are you taking the least restrictive action necessary to achieve the aim? Have you considered all the alternatives?

A human rights approach to decision-making

This section of the guide supports you to apply human rights your practice. It sets out models and examples for using human rights as a framework for decision making so that you can best support the young autistic people or young people with a learning disability you work with. This section of the guide includes the following:

FAIR model:

This is a human rights decision-making framework that you can adapt to suit your practice so that you can make sure you are upholding human rights for young autistic people and young people with a learning disability.

Using human rights: flowchart for identifying a human rights issue:

Many situations in your work are likely to engage human rights in some form. As a practitioner you will be making decisions that are likely to impact on the rights of the young people you are supporting and their families and carers. You may also be making decisions that impact on the rights of your colleagues, and your own rights.

The flowchart in the guide gives you some simple steps to follow to embed human rights within your decision making. Once you feel confident about using human rights to inform your decision making you could even try to adapt the flowchart for a specific purpose e.g. care planning.

Spotlight on adopting a human rights approach to supporting young autistic people and young people with a learning disability in three scenarios:

This section of the guide explores adopting a human rights approach to three specific areas:

- transition from child to adult services;
- education; and
- care planning.

These three focus areas are looked at through a human rights lens, exploring how rights should be thought about, highlighting relevant human rights, and using a case study to illustrate how rights-based decision-making works in practice.

FAIR Model

FAIR* is a human rights decision-making framework that practitioners can use to ensure that their decisions, policies and practice uphold people's human rights. In this resource we explain the key parts of the FAIR model but you can adapt this to your practice and include additional bullet points for each section.

*FAIR is a model developed by the Scottish Human Rights Commission

FACTS:

- what are the key facts? What do you still need to find out?
- what is the impact on the young person, their families and carers? What are their views? What have they told you about the impact on them?
- are there other practitioners or agencies that you need to speak with to get more information?

ANALYSIS:

- which rights are risk?
- are these rights absolute or non-absolute?
- remember, there is no legal justification for interfering with an absolute right. This would be a breach of the law.
- if non-absolute, work through the three stage test: Lawful? Legitimate? Proportionate? (Remember, you will need to work through this test for each non-absolute right engaged)

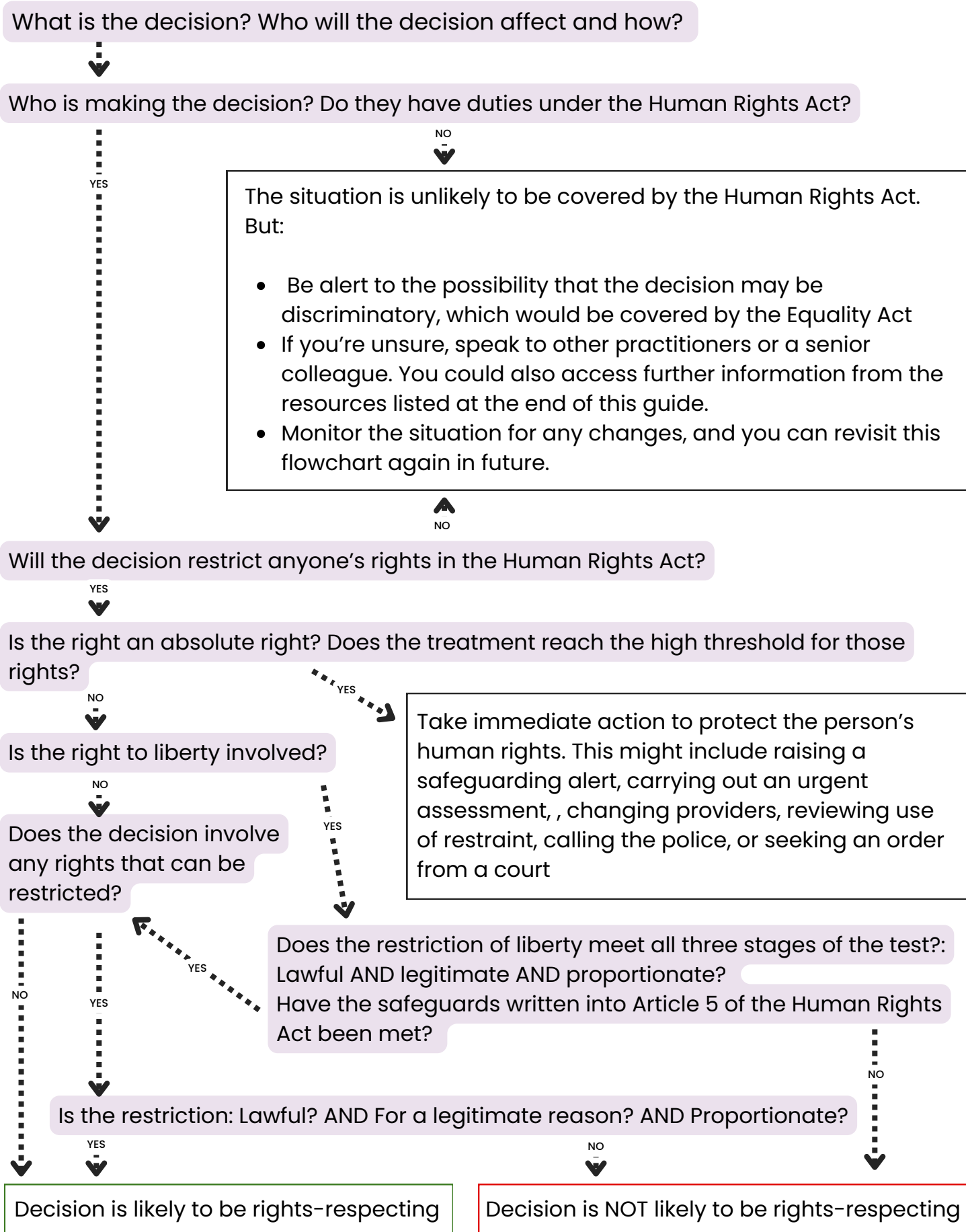
IDENTIFY ACTIONS:

- involve the young person in these discussions.
- what could be changed to make it more rights respecting?
- why should these changes be made?
- who has responsibilities for making changes?
- when do these decisions need to be made by?

RECORD AND REVIEW:

- how can the actions taken be recorded and reviewed and how will you involve the young person?
- who needs to be involved in the review?
- when does this decision need to be reviewed by?

Identifying human rights in decision-making





Spotlight on: Transition from child to adult services

Young autistic people and young people with a learning disability who are accessing mental health support will often go through a transition from children to adult services. At a time in their lives which is full of physical and emotional change, these young people must also navigate a change from established services, often provided by individuals they know and feel comfortable with, to new support from new providers. It may also be the case that far less and/or very different support is available to them as adults. Practitioners supporting young autistic people and young people with a learning disability must be aware of the potential risks to rights during this transition period so that they can ensure that the appropriate support is in place to safeguard these rights. This is likely to involve exploring options for appropriate service provision, making space for autonomy, growing independence and risk taking, joined up working with other services and recognising that there may be family members and loved ones who are perhaps not used to their child taking on more of a decision-making role.

Potential human rights issues in practice



- transition plans made with little involvement with the young person or their family and with no measures put in place to support them to take part
- if transition planning is very last minute or not well communicated and the uncertainty and change impacts on the young person's wellbeing
- rights not being looked after because there is disagreement between adult and children's services over who has responsibility and no joined up working is in place
- long delays to transition planning which cause additional distress and uncertainty to the young person which might lead to dysregulation.

A human rights approach to planning transitions from child to adult services:

- thinking about advance planning, is the transition process being started early enough to make sure that it is comprehensive and that rights are being considered? Has the process been explained to the young person and their family so that they know what is going to be involved and can fully take part?
- thinking about how to best involve the young person so that they are involved in these significant decisions about their lives. [NHSE guidance for meeting the needs of autistic adults in mental health services](#) states “Each autistic person should be at the centre of their own transition and be supported to participate from the outset”.
- if a person is assessed as lacking capacity to make decisions about their care, having genuine regard to their views, values and sense of identity when working out what may be in their best interests.
- recognising that transition planning is about recognising the needs of a young person developing into an adult with a greater independence, with increasing autonomy over decisions about relationships, work, education and where they want to live. As part of this, considering whether the plan allows for proportionate approaches to risk and whether there are unnecessary restrictions to the young person’s freedom to make their own decisions.
- acknowledging that this is a time of uncertainty in which young people will be moving to different services or working with different individuals. In some cases, the support provided will be significantly decreased. What steps can be put in place to minimise the impact that this will have on the wellbeing of the young person, especially if they find change particularly challenging?
- exploring meaningful age-appropriate activities for young people if this is important to them and discussing the options with the young person and their family.
- considering accessibility and making sure that transition plans are made and communicated in a way that the young person and their family can best understand and contribute to.

- recognising that there are a likely to be several professionals with human rights duties involved and establishing joined up approaches to working to ensure that rights are being thought about by all.

A human rights based approach: an example from practice



Maryam's story

Maryam is an autistic 16-year-old with a learning disability. Maryam has difficulty processing and understanding information; routine and familiarity are very important to her and changes can escalate her anxiety. Maryam has also been displaying a number of behaviours of concern which have intensified over the past couple of years.

Maryam lived at home with her mum and 2 sisters; her parents are separated, and she also has an older brother who lives in a residential care setting. Maryam and her younger sibling have been the subject of Child Protection planning concerns linked to exposure to parental domestic abuse and, parental neglect of their basic care needs. Maryam will physically attack both her mum and her younger sister when she is very anxious and has also self-harmed.

After some work by multiple professionals, it was identified by all involved with the family that Maryam needs to live somewhere other than the family home, but also somewhere that allows her to continue to access her school (where she feels safe and supported) and also to see her family regularly.

What was the approach taken?

All agencies were in agreement that Maryam should be at the heart of any decision making around living arrangements: once a placement is identified, pictures will be taken for Maryam so that she can see where she is going and there will be a gradual induction period which will introduce Maryam to her surroundings and her support staff very slowly so that she can become familiar with them. Using a rights-based approach took Maryam's care through a **specific framework which centres on having personalised support underpinned by human rights**. The Mental Capacity Act alongside the Human Rights Act is fundamental to this approach in supporting decisions which are available to Maryam.

The approach allowed the practitioners involved to view the support through the lens of necessity and proportionality, which in turn led to resources being directed to what the specific care planning should look like.

For Maryam this ultimately led to some support being deemed necessary and other restrictions being more about the anxieties of the care provider or other members of the MDT. Because the care she received reduced, the MDT could explore more options for accommodation, and Maryam had more scope to be included in educational settings. This led to Maryam being able to live successfully in her own flat within a supportive care environment.

Had this rights-based approach not been adopted the trajectory could quite easily have led to defensive decision making from the care management team involved which could likely have led to Maryam being placed in an out of area residential care setting with very high levels of supervision and control and with limited access to education.

Key rights to consider



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

(protected by Article 8 in the Human Rights Act).

This right includes protections of people's wellbeing, autonomy, access to the community, relationships, family and enjoyment of their home. In transition support this could involve a young person:

- making choices about their own life, even if it differs from the wishes of their loved ones or people providing support
- being offered the appropriate support when in crisis
- having access to what they define as their community, this might include spending time with their peers, pursuing hobbies, interacting with their online or social media communities
- being supported to develop their independence and explore age-appropriate risk taking
- developing or exploring relationships, including sexual ones
- being able to maintain meaningful relationships with their family

Relevant practitioner duties

- To **respect** this right: not interfering where possible, unless it is lawful, for a legitimate reason and proportionate.
- To **protect** this right: taking action to protect where necessary.
- To **fulfil** this right: when the right has been risked or breached understand why and prevent this from happening again with improved practices and processes?



The right to be free from inhuman or degrading treatment (protected by Article 3 in the Human Rights Act).

This right protects people from serious abuse or neglect which causes mental or physical harm or humiliates them. When transition planning this could cover:

- taking reasonable steps to prevent serious harm to a young person (either from others or themselves)
- assessing if there will be very severe impact on a young person if provision is withdrawn or significantly changed as a result of moving to adult services
- serious interventions to protect a young person's right to life which could lead to inhuman and degrading treatment.

Whether something is 'inhuman or degrading' depends on the impact on the person. Consider their personal circumstances such as their age, mental or physical health, previous experiences of trauma etc

This is an absolute right which means there is never a lawful justification for interfering with this right, any interference with the right to be free from inhuman and degrading treatment will breach Article 3.

Relevant practitioner duties

- To **respect** this right: not breaching it in any circumstances.
- To **protect** this right: taking action to protect someone from a known and immediate risk of serious harm, often called safeguarding.
- To **fulfil** this right: when the right has been risked or breached understand why and prevent this from happening again with improved practices and processes?



The right to peaceful enjoyment of possessions

(protected by Article 1, Protocol 1 in the Human Rights Act)

This right protects people's access to, and enjoyment of their possessions (including money). When transition planning this could involve a young person:

- receiving the benefits they are entitled to, free from restrictive conditions about how they spend their money
- having access to their personal possessions such as toys, books, smart phone, computers etc.

Relevant practitioner duties

- To **respect** this right: not interfering where possible, any interference would have to be lawful, for a good reason and proportionate.
- To **protect** this right: taking action to protect where necessary.
- To **fulfil** this right: when the right has been risked or breached understand why and prevent this from happening again with improved practices and processes?



The right to be free from discrimination

(protected by Article 14 in the Human Rights Act).

This is a right not to be discriminated against in relation to any of the rights contained in the Human Rights Act. This could cover:

- a young person being prevented from accessing appropriate adult services because they are autistic or have a learning disability
- assumptions made about a young person based on their “behaviour” without recognition that the process of transition may be making it difficult for them to manage their emotions
- a young person not being able to take part in their own transition planning as it has not been made accessible for them e.g. in communication style and format.

The right to be free from discrimination in the Human Rights Act sides alongside the protections in the Equality Act 2010, and in the case of disability discrimination the need for reasonable adjustments.

Relevant practitioner duties

- To **respect** this right: not limiting it is unless it is for a legitimate aim and it is the least restrictive option.
- To **protect** this right: taking into account that sometimes people need to be treated differently, because their situation is different.
- To **fulfil** this right: when the right has been risked or breached understand why and prevent this from happening again with improved practices and processes?



Worked example: Jared

Jared is 16 and is autistic. At the age of 14 Jared was admitted to a psychiatric unit for drug induced psychosis. He stayed there until he was 15, when he was discharged back to his family home. Recently, there was a violent incident at home where Jared lashed out at his mother. He remains close with his mother and sister but understands that his dad will not allow him to continue living at home.

Jared has capacity to make decisions about where to live, finances, care and treatment. He wants to go to college, has career aspirations and would like a home with sensory adaptations. Both adult and child services are involved as they need to plan for Jared's transition into adult services.

Jared is provided with a supported living space in a block of flats; with 3:1 support and additional staff available from other flats for authorised restraint. Jared does not have unsupervised access to his kitchen or bathroom due to self-harm concerns. His mother and sister have made it clear Jared needs culturally appropriate support and to be involved with his church, but he is 30 miles away.

Jared had said that education is important to him, and he wants to attend college and has ambitions for a career in human resources. There have been ongoing discussions about tutoring or specialist provision to allow him to return to education, but the local college is uncertain about allowing him on their site following discussions with his provider.

APPLYING FAIR

Facts: Jared is 16 and is autistic and both adult and child services are involved in his support as they are planning for transition. He has capacity to make decisions about where to live, finances, care and treatment. He is living in a supported living space and hopes to go to college. He has 3:1 support and there are additional staff available for authorised restraint. There are concerns about self-harm. Jared's family want him to have culturally appropriate support and to be involved with his church, but he lives far away. Jared wants to attend college to work in human resources in the future, but it has not been possible to support him to access college yet.

Analysis:



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

Absolute human right – no restriction on this right is lawful.

This right could be engaged depending on the severity of Jared's self-harm and the impact that this has on him. It is important to explore the impact on Jared from the authorised restraint, particularly as this requires additional staff who Jared may not know as well as his usual support.

Jared does not have unsupervised access to his bathroom. Is he completely reliant on staff in order to use washing and toileting facilities? What is the impact of this on Jared?

Practitioners could decide to continue to monitor the impact on Jared if they believe this right is not currently at risk but could be in the future if such high levels of restrictions continue or if the restrictions are continued irrespective of continuing need.



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

This right is engaged in terms of Jared's physical and mental wellbeing, his autonomy, his relationships with others, enjoyment of his home and access to his community

Wellbeing: The use of restraint is likely to impact on Jared's wellbeing.

Autonomy: It is not clear how much choice Jared has about important life decisions or the current support provided in his home e.g. are there the sensory adaptations in his home that he has asked for? Jared's family have said that it is important for Jared to attend his church, but it is not clear if this is what Jared wants too. Jared has talked about his aspirations for his education and future career but there is no support in place to help him to achieve this.

Community: If Jared does want to access his church community this is currently difficult because he lives far away. Jared wants to be part of a college community but there is currently no provision in place for him to access college education.

Enjoyment of home: Jared is not able to access all of the rooms in his home due to concerns about self-harm.

Article 5: The right to liberty

Jared's freedom of movement is limited as he has 3:1 support at home, with additional staff on hand for authorised restraint. He is also not able to access certain rooms in his own home.

There is no mention of the legal basis for these restrictions – but even if there is the 3-stage test still needs to be met: lawful, legitimate aim, proportionate. The procedural safeguards within this right must also be applied.

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

Jared's family have identified the importance of culturally appropriate support and being able to access his church. Is the current type of support in place restricting Jared's right to manifest his religious and cultural beliefs?

Think proportionality: Are the child and/or adult teams working with Jared and his family to explore alternative support options that respect his cultural and religious beliefs?

Article 2, Protocol 1: The right to education

Jared wants to go to college, but nothing is in place. He has a right to access education that already exists including higher education.

If Jared and his family have concerns about making sure his religious and philosophical beliefs are respected by education provider this could also be explored with the potential college.

Think proportionality: What are the concerns from the college about allowing Jared onsite? How can these be addressed and what can be put in place to support Jared to attend?

Article 14: The right not to be discriminated against

Is Jared being treated differently because of his autism and mental health history or perhaps because of his religious beliefs? Is there an objective and reasonable justification for this?

Identify actions:

- there is a shared legal duty across child and adult services; what could be put in place to support collaborative working?
- work with Jared to identify what is most important to him.
- what other alternatives are there to the restraint?
- what support can be put in place around Jared's self-harm?
- potential review of the 3:1 support ratio and limitations on access to certain rooms, what other ways are there to keep Jared safe?
- does Jared's home have the sensory adaptations that are important to him?
- what could be done to support Jared to access his religious community? Is he able to interact with his church online, can transport and support staff be put in place so that he can attend his church? Are there alternative accommodation options that would mean that Jared lives closer to church?
- how can the college concerns be addressed and how can Jared be supported to attend?

Record and review:

- Record all actions and show how you have considered rights.
- Share any actions and plans across both child and adult services.
- Review actions together with Jared and his family and monitor the impact on any rights.



Spotlight on: Education

Young autistic people and young people with a learning disability have the same human right to education as everybody else. Education plays a key role in supporting young people to learn new skills, access information, develop relationships with their peers, access their community and to increase their independence.

It is likely that practitioners supporting young autistic people and young people with a learning disability will have to navigate issues around education that might engage a number of human rights. This may involve, for example, supporting young people to access suitable education in the community or inpatient settings or it may require a practitioner to advocate for young people whose rights are potentially at risk within education settings themselves.

Potential human rights issues in practice



- young people not being able to access suitable primary, secondary and higher education either in community or inpatient settings.
- young people without adequate transport provision to support them to attend school or college.
- young people who do not have suitable care provision to support them to attend school or college.
- a young person being unable to access items which are needed for educational purposes when in an inpatient setting e.g. education materials, internet, computers, pens, paper
- school policies that are not inclusive such policies about behaviour that don't make allowances for individual needs.
- use of seclusion and restraint in educational settings
- a young person who is excluded from school because they are autistic and/or have a learning disability.

Key rights to consider



The right to education

(protected by Article 2, Protocol 1 in the Human Rights Act)

The Government has a duty to provide access to education that already exists for all children and young people up to the age of 18 in the UK. This includes:

- a young person being able to access primary, secondary or higher education
- a young person being able to access suitable education e.g. if they have any special educational needs, they should be able to attend a school that provides suitable support for them to learn.
- making suitable provisions for inpatient or hospital school for a young person to carry on with their education and to obtain their obtain qualifications such as GCSE's or A-levels.
- thinking about a young person's (or their parents') religious or other beliefs and principles in relation to their education.

Relevant practitioner duties

- To **respect** this right: not interfering with a child or young person accessing education unless it is lawful, for a legitimate aim and proportionate.
- To **protect** this right: taking reasonable and appropriate steps to protect a child or young person's right to education.
- To **fulfil** this right: when the right has been risked or breached understand why and prevent this from happening again with improved practices and processes?



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

(protected by Article 8 in the Human Rights Act)

The right to private life protects people's wellbeing and autonomy including:

- a person having control over their own life including making choices about education
- a person having access to what they define as their community which could include a school community
- any potential risks to a person's wellbeing because they are unable to continue with their education.

Relevant practitioner duties

- To **respect** this right: not interfering where possible, unless it is lawful, for a legitimate reason and proportionate.
- To **protect** this right: taking action to protect it where necessary.
- To **fulfil** this right: when the right has been risked or breached understand why and prevent this from happening again with improved practices and processes?



The right to be free from discrimination

(protected by Article 14 in the Human Rights Act)

This is a right not to be discriminated against in relation to any of the rights contained in the Human Rights Act. This could cover:

- a person being prevented from accessing school because of they are autistic or have a learning disability.
- a school refusing to adapt a policy to account for someone's needs due to their learning disability or because they are autistic e.g. allowing fidget toys in class.

- a person not being able to access education provision that takes into account their religious beliefs.

The right to be free from discrimination in the Human Rights Act sides alongside the protections in the Equality Act 2010, and in the case of disability discrimination the need for reasonable adjustments.

Relevant practitioner duties

- To **respect** this right: not limiting it is unless it is for a legitimate aim and it is the least restrictive option.
- To **protect** this right: taking into account that sometimes people need to be treated differently, because their situation is different.
- To **fulfil** this right: when the right has been risked or breached understand why and prevent this from happening again with improved practices and processes?





Worked example: Evie

Evie is a 17-year-old girl detained on a CAMHS ward under Section 3 of the Mental Health Act. She has ADHD and is autistic. Evie has an A-level maths exam coming up and is worried about it. Evie becomes increasingly anxious about the exam and her behaviour begins to change. On several occasions she attempts to abscond from the ward and staff decide to take her leave away as they are worried about her safety if she tried to do so again. As a result, Evie is no longer able to attend the hospital school next door. Evie becomes even more anxious about her maths exam and is worried she will not pass it without going to school and due to her ADHD, she struggles to stay focussed without prompts from her teacher. Her behaviour escalates and she is physically aggressive towards others and after trying to stab a staff member with a pen she is restrained and placed in seclusion.

In the seclusion room Evie remains very distressed. She continues to worry about her maths exam and does not know if she will still be able to take it or when she will get out of seclusion. She is unable to study for the exam as she is not allowed access to items to support her to study and does not have pen and paper to make any notes.

APPLYING FAIR

Facts: Evie's is detained on an inpatient CAHMS ward, is autistic, has ADHD. Her exam related stress is causing her behaviour to escalate. Due to concerns that Evie might abscond her leave has been taken away and after being physically attacking a staff member she has been secluded. Evie is not able to access the hospital school or prepare of her upcoming exam and is very distressed.

Analysis:



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

Absolute human right – no restriction on this right is lawful.

This right is potentially engaged depending on the severity of the impact of the seclusion on Evie.

What is the impact on Evie of being secluded without knowing when it will finish or how she will prepare for her exam (or if she will even still be able to take it). Is there anything about Evie or her previous experiences that would make the seclusion particularly distressing?

Practitioners should continue to monitor the impact on Evie if they believe this right is not currently at risk but could be in the future if the seclusion continues.



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

Evie's wellbeing, autonomy and access to the community is potentially at risk as a result of her increasing exam related stress, the decision to take away her leave and the use of seclusion.

This right is non-absolute, but any restriction of this right must pass the 3-part test of lawful, legitimate aim and proportionate.

Think proportionality: what can be put in place to support Evie to manage her exam related stress? How can she still be supported to feel part of her school community despite not being able to attend lessons? Could practitioners explore the possibility of postponing the exam but reassure Evie that she could take it in the future?



Article 5: The right to liberty

Evie's freedom of movement is being limited through taking away Evie's leave and the use of seclusion.

This right is non-absolute, but any restriction of this right must pass the 3-part test of lawful, legitimate aim and proportionate. Practitioners also need to check that the safeguards written into this right have been met.

Think proportionality: Is this use of seclusion the most appropriate way to support Evie and keep her safe? Could practitioners explore other ways to deescalate Evie's behaviour or find out more about why she is so upset? Have practitioners found out from Evie why she has tried to abscond from the ward? Is there an option for reinstating her leave but being accompanied by staff to attend the hospital school?



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

Evie is not able to access items that she needs to prepare for her maths exam such as a laptop or paper and pencils.

This right is non-absolute, but any restriction of this right must pass the 3-part test of lawful, legitimate aim and proportionate.

Think proportionality: How can Evie safely access her materials? If this is not possible what other ways are there for Evie to revise her maths or do school work?



Article 2, Protocol 1: The right to education

Evie is not able to access education on the ward as her leave has been taken away and she is in seclusion.

This right is non-absolute, but any restriction of this right must pass the 3-part test of lawful, legitimate aim and proportionate.

Think proportionality: What could be put into place to support Evie to continue with her maths education? Could the teacher come to Evie?



Article 14: The right not to be discriminated against in relation to other human rights

Evie is autistic and has ADHD and is a young person. Practitioners must reflect on whether they are treating her differently because she is autistic and whether there is an objective and reasonable justification for this.

Should additional measures have been put in place for Evie because she is autistic and has ADHD, which would have supported her to manage her exam anxiety?

Identify actions:

- review of Evie's seclusion and if it is not possible to end it immediately make a plan for a route out of seclusion
- involve Evie, her loved ones, practitioners who know Evie best and are trained in supporting autistic young people in the review and future planning
- explore support to reduce Evie's exam related stress. For example, whilst in seclusion, her teacher could come to speak to her about the exam and make a plan with her about it
- once out of seclusion, review the decisions to suspend Evie's leave. If it is still not possible for Evie to have her leave, other alternatives could be explored. For example, arrangements could be made for the teacher to come to the ward and use a communal space to do maths with Evie and help her to prepare for the exam.
- adjusting Evie's care plan together with Evie to put in place more appropriate support and de-escalation points for any future exam related stress.

Record and review:

- Record all actions and review regularly together with Evie, especially Evie's seclusion (if it continues) and the decisions about Evie's leave.



Spotlight on: Care planning

Care planning plays a crucial part in making sure that young autistic people and young people with a learning disability get the appropriate support for their individual needs. Embedding human rights within care planning approaches supports practitioners to ensure that care plans place the person at the centre. This means that care plans will reflect the young person's needs and views and that any decisions about restrictive interventions are rights respecting and appropriate for that individual.

Potential human rights issues in practice



- if young people are not included in the care planning process
- if care packages are highly restrictive and based perhaps more on assumptions about a young person or blanket way of working rather than that person's individual level of risk
- if providers refuse to deliver care plans or deliver something very different to what was agreed
- if care plans are not shared or looked at by other practitioners.

A human rights approach to care planning:

- placing the young person at the heart of the care planning and ensuring that their right to make decisions about their life is protected
- if a young person is assessed as lacking capacity to make decisions about their care, having genuine regard to their views, values and sense of identity when working out what may be in their best interests

- speaking to the young person and their loved ones to find out more rather than deciding what they need based on their case file. This is exploring who they are, what is important to them, what their hopes for the future are and what makes them feel anxious or worried.
- recognising fluctuating needs and risk and embedding flexibility within the care plan so that interventions that restrict non-absolute rights are only made when necessary and absolute rights are not breached
- ensuring care plans are regularly reviewed so that they continue to meet the needs of the young person and that rights are not at risk if anything has changed
- applying a human rights framework to ensure that provisions are not overly restrictive. For example, what is the impact on rights if a care plan includes provision for someone to live in the community but have a high ratio of staff
- applying a human rights framework to ensure that provisions are not overly restrictive. For example, what is the impact on rights if a care plan includes provision for someone to live in the community but have a high ratio of staff supporting them at all times, including when going out? Is there potentially a deprivation of liberty?
- challenging providers if they argue that support can only be provided in a very restrictive way
- being open and transparent about the care planning process and the care plan itself. Making sure that you explain why you have put certain provisions in place and if the young person or their family is not happy with a decision, explaining why you have done so and showing how you have thought about human rights.

Key rights to consider



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

(protected by Article 8 in the Human Rights Act).

This right protects people's autonomy, wellbeing, relationships and enjoyment of their home, including:

- young people having control over their own lives, including being able to make decisions considered by others to be unwise.
- young people being able to make personal choices about their lives including the community they want to access, what they do with their money and who they have relationships with
- young people having a say about where they live or how they feel about moving to new accommodation

Relevant practitioner duties

- To **respect** this right: not interfering where possible, unless it is lawful, for a legitimate reason and proportionate.
- To **protect** this right: taking action to protect when necessary.
- To **fulfil** this right: recognising that care planning is ongoing and live, so if things have gone wrong, working with the young person to work out why and adapting the care plan to prevent future unnecessary interferences with the right.



The right to be free from inhuman and degrading treatment

(protected by Article 3 in the Human Rights Act)

This right protects people from serious abuse or neglect which causes mental or physical harm or humiliates them. When making decisions about care plans this could cover:

- taking reasonable steps to prevent serious harm to someone (either from others or themselves)
- serious interventions to protect the right to life which could lead to inhuman and degrading treatment.

Whether something is 'inhuman or degrading' depends on the impact on the person. It is important to consider their personal circumstances such as their age, mental or physical health, previous experiences of trauma etc.

This is an absolute right which means there is never a lawful justification for interfering with this right, an interference will be breaching it.

Relevant practitioner duties

- To **respect** this right: not breaching it in any circumstances.
- To **protect** this right: taking action to protect someone from a known and immediate risk of serious harm, often called safeguarding.
- To **fulfil** this right: when the right has been risked or breached understand why and prevent this from happening again with improved practices and processes?



The right to life

(protected by Article 2 in the Human Rights Act)

This includes a positive obligation on practitioners to take reasonable steps to protect a someone's life where it is known to be at real and immediate risk (or they should have known life was at risk).

This is an absolute human right, this means everyone's life must be protected in law and through the actions and decisions of public officials. They can also be responsible for failures to protect life.

Relevant practitioner duties

- To **respect** this right: not breaching it in any circumstances.

- To **protect** this right: taking reasonable steps to protect life where necessary, including when someone in your care is in real and immediate risk either from themselves/others.
- To **fulfil** this right: robustly investigating any deaths or risks to life and ensuring lessons are put in place to prevent this in future.



The right to liberty

(protected by Article 5 in the Human Rights Act)

This right prevents extreme restrictions being placed on people's movement, except in specific circumstances (such as a Deprivation of Liberty (DoL) Authorisation or detention under the Mental Health Act. Even if a restriction on liberty is for a lawful reason, there are still human rights safeguards which must be in place. Restrictions on liberty might include:

- if someone is living in their own home but is unable to move around their home unsupervised or without permission
- if there is an order in place restricting someone's movements or access to spaces (eg. DoL Authorisation or MHA section applied) and this is applied without the Article 5 safeguards.

Relevant practitioner duties

- To **respect** this right: not interfering where possible.
- To **protect** this right: applying the procedural safeguards written into the right.
- To **fulfil** this right: when the right has been risked or breached understand why and prevent this from happening again with improved practices and processes?



The right to be free from discrimination

(protected by Article 14 in the Human Rights Act)

This is a right not to be discriminated against in relation to any of the rights contained in the Human Rights Act. This could cover:

- not providing the appropriate services for an individual's needs.
- not taking steps to make care planning accessible to the young person e.g. through Easy Read materials, explaining the process, providing an interpreter.
- making assumptions about a young person's ability to maintain relationships, access work, interact with the community or pursue hobbies and interests as part of their care plan based on their characteristics such as age or disability.

The right to be free from discrimination in the Human Rights Act sides alongside the protections in the Equality Act 2010, and in the case of disability discrimination the need for reasonable adjustments.

Relevant practitioner duties

- To **respect** this right: not limiting it is unless it is for a legitimate aim, and it is the least restrictive option.
- To **protect** this right: taking into account that sometimes people need to be treated differently, because their situation is different.
- To **fulfil** this right: when the right has been risked or breached understand why and prevent this from happening again with improved practices and processes?



Worked example: Jane

Jane is an autistic 22-year-old. She has had 2 previous admissions to mental health inpatient units. Jane experienced significant uses of restraint and seclusion as an inpatient due to incidents with staff, and serious self-harm. The restrictions included being placed in rooms off the ward/denial of access to the wards, and exclusion from education and leisure options.

The Court of Protection found that Jane had capacity for decisions about her living arrangements, care and relationships. In planning for discharge, the recommendations (from Jane's MDT) included living independently from her parents, in a home adapted for her sensory needs, with supervision of phone and laptop, access to reduce risk of ordering poisons, and support to prevent self-harm and harm to others including risk of physical confrontations with staff and absconding.

Current situation:

Jane has been discharged to a self-contained flat in a specialist block. Jane has 4:1 staffing, and the support provider has flagged considering the need for additional staff if prone restraint (a physical intervention where a person is held face down with their arms and legs restrained) is needed to manage escalations in behaviour. They are also considering door security and monitoring of post to reduce the risk of harmful substances being delivered.

Jane wants to work and has been applying for roles online. She has also been meeting people on online dating sites. She wants to go to job interviews and on dates with people she has met online.

The care provider wants additional guidance about these issues so Jane's MDT meet with the care provider and Jane. Jane says she resents having so many staff around her, she feels that their presence 'oppressive' and 'makes me look strange and dangerous'. She feels it's 'just like hospital where they were always watching me'. Jane's Case Manager is concerned that the current care plan may not be respecting or protecting Jane's human rights. She uses the FAIR framework to identify and understand which of Jane's human rights are engaged. She shares this with the MDT, the care provider and Jane to advocate for a care plan that respects and protects Jane's rights.

APPLYING FAIR

Facts: Jane is an autistic 22-year-old living with support in a self-contained flat. Jane has capacity to make decisions about her living arrangements, care and relationships. Jane is trying to find work and start online relationships. She has a substantial care package of 4:1 staff who supervise her phone and laptop access. The care provider plans to monitor Jane's access to the front door, her post and to put in additional staff for prone restraint. Jane experienced significant uses of restraint and seclusion as an inpatient due to incidents with staff, and serious self-harm. When asked about her current care arrangements Jane has describes it as "just like hospital where they were always watching me".

Analysis:



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

Absolute human right – no restriction on this right is lawful.

Prior experiences of restraint and seclusion may have caused trauma. What is the impact of the restrictions and exclusions continuing in Jane's own home? She has indicated that the current situation feels 'just like hospital and has described the significant levels of observation she is under as 'oppressive'.

The care provider is planning for the use of prone restraint. There is a risk that the use of prone restraint could breach Jane's Article 3 rights.



Article 2: The right to life

Absolute human right – no restriction on this right is lawful.

Jane has historical self-harm experiences and there are ongoing concerns about risk including Jane accessing poisons via post. If practitioners believe that Jane's right to life is at real and immediate risk, they must take reasonable steps to prevent Jane taking her own life.

In this scenario, the absolute Article 3 right and the positive obligations imposed by Article 2 may both be engaged. Practitioners would therefore need to ensure that measures designed to protect the right to life do not amount to or involve inhuman and degrading treatment for Jane based on her individual situation. Article 3 is an absolute right but actions which may breach that right in some circumstances may not in others (such as where life is threatened)



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

This right is engaged in terms of Jane's physical and mental wellbeing, her autonomy, her relationships with others, enjoyment of her home, access to her community and communication with others.

Wellbeing: even if the harm associated with trauma, self-harm, and restraint don't reach the threshold for Article 3, they impact Jane's physical and mental wellbeing which engages her Article 8 rights.

Autonomy: it is important to consider what involvement Jane has in her care planning. What are her choices? Jane's voice needs to be central in her care plan.

Relationships with others: Jane is meeting people online and seeking dates, but how will this always be possible with significant staffing around her at all times?

Communication with others and confidentiality – access to items that enable staying connected, including mobile and laptop. Supervision of use of these and also monitoring of her post.

This right is non absolute, but any restriction of this right must pass the 3-part test of lawful, legitimate aim and proportionate.

Think proportionality: How can the impact on Jane's right to private and family life be reduced? What alternatives are there? For example, what could be put in place to reduce the need for physical restraint? Are there certain locations in which the risk to Jane can be managed with less staff?

Article 5: The right to liberty

Jane's freedom of movement is severely limited within her home and in the community. The care provider are also considering monitoring access to the front door which would restrict her ability to leave.

There is no mention of the legal basis for these restrictions – but even if there is, the 3 stage test still needs to be met: lawful, legitimate aim, proportionate. The procedural safeguards within this right must also be applied.

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

Jane cannot access her phone or laptop unless staff retrieve them from a locked cupboard and supervise her using them.

This right is non-absolute, but any restriction of this right must pass the 3-part test of lawful, legitimate aim and proportionate.

Think proportionality: How can Jane safely access her phone and laptop? Can Jane be involved in making agreement about when and how she uses her phone and laptop?

Article 14: The right not to be discriminated against in relation to other human rights

Is Jane being treated differently because she autistic and because of her previous history and reputation for self-harm and aggression towards others. Is there an objective and reasonable justification for this?

Identify actions:

There is a shared legal duty across the practitioners in this scenario. Practitioners need to take steps to address the rights in question, making sure absolute rights are not breached and that restrictions of non-absolute rights meet the three stage test. This could include:

- exploring alternatives for ensuring safety of Jane and staff without restraint
- making sure that Jane is fully included in care planning and decisions about what will happen next
- not stepping in when Jane is making unwise but lawful decisions
- reviewing the monitoring of phone and laptop use and also the post
- recognising the impact of the significant observations/staff ratio and exploring alternative options together with Jane so as to reduce any harm being caused.
- ensuring that there is no unlawful deprivation of liberty.

Record and review:

Record all actions and review the care plan regularly together with Jane, especially Jane's risk assessments and decisions around restrictive practice.

Useful BIHR resources

There is a wide range of information about human rights on the BIHR [website](#). In particular you might find the following of particular interest:

[The 16 rights in the Human Rights Act](#)

[Section by section guide to the Human Rights Act](#)

[The principle of universality](#)

[Eating Disorder Awareness Week: Human Rights in Treatment](#): a blog discussing how to approach balancing decisions about absolute rights

[Learning Disability, Autism and Human Rights: An accessible guide](#)

[Mental Health, Mental Capacity, My Rights: An accessible guide](#)

[Embedding human rights in mental health services: A tool for staff](#)

BIHR have a range of resources that you can download from the [resource page](#) on our website.

You can download lots of Easy Read versions of BIHR's information and resources in the [Easy Read Hub](#) on the BIHR website.

If you found this guide helpful, or if you have feedback about the contents, we'd love to hear from you. Send us your comments, suggestions and stories of human rights in your practice at info@bihr.org.uk.