The British Institute of Human Rights
bihr.org.uk

Learning Disability, Autism and Human Rights

Accessible resource

What is this booklet?

This booklet is about learning disability, autism and human rights.

This booklet aims to give you information about how human rights can help you to have **more control over your own life** and be **treated with dignity and respect**.

This booklet explains your human rights when you are receiving **health, care and social care services**, e.g. at your GP, in hospital, community care, care homes etc.

This information can also help you with

This booklet explains how you can decide if a concern you have is a human rights issue.

It gives you suggestions of what you can do if your human rights are not respected.

It gives suggestions about how you can use human rights to overcome these challenges using real life examples.

(If you see this picture, it means the story is a real life example from our work)

Who is this booklet for?

This booklet is for anyone living with learning disabilities and / or autism.

It will also be useful for anyone who supports a person living with learning disabilities and / or autism.

This booklet covers both learning disability and autism because there is often some overlap between the two.

Also, people living with learning disabilites and / or autism will often be using similar types of services. The information in this booklet aims to be relevant for both.

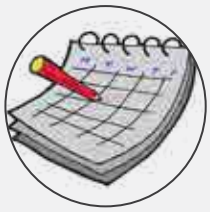
The aims of learning disability and autism services should support human rights values.

You can see what we mean by learning disability and autism on the next page.

Learning disability

When we talk about someone having a learning disability we mean someone who may take longer to learn and understand things.

Other people may also take longer to understand them too.



There are lots of different words used to describe people with learning disabilities. Words like ‘complex needs’ or ‘high support needs’ sometimes are used to refer to people who need a lot of support to live their daily lives.

Other people may only need a few hours support to do certain things, like writing letters or paying bills.

No two people with learning disabilities are the same.

Some people like the words ‘learning disability’ to describe this, but some others like ‘learning difficulties’. We choose to use learning disability in this book.

Autism

Autism is sometimes called the Autistic Spectrum. This means there are lots of different ways autism affects people.

You can think about autism as a difference in the way a person thinks and understands the world and other people.

Being on the Autistic Spectrum can mean that the person may communicate differently and understand situations differently.

Autism is not a learning disability or a mental health issue.

Some people may react to noise, light and touch in a different way too.

No two people with autism are the same.

Finding your way around the booklet

This booklet contains nine sections:

What are human rights? Page 8

Who has human rights? Page 9

How are my rights protected? Page 10

Who has duties to uphold my rights? Page 12

What rights do I have?

Right to life Page 16

Right to be free from inhuman and degrading treatment Page 19

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Flowchart 1:
Is my issue about human rights? Page 43

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Getting more help and information

- Where can I get more help? Page 69
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Word list

Abuse: this is about you being safe and not being hurt or neglected by other people

Capacity: this is about your everyday ability to make decisions about what happens to you

Choice: this is being able to make decisions over your own life. This is sometimes also called autonomy

Consent: this is about you being able to agree to your own care or treatment

Control: this is about you being in charge of your own life

Detained: being held somewhere and not allowed to leave

Dignity: this is about you being treated like a person and not an object

Duties: these are the things the law says someone must do

Family: this is about your relatives and close friends

Law: laws set the rules about how you should be treated

Legitimate: there is a good reason and it is allowed, for example by a law

Liberty: this is being able to move about without being stopped

Positive duty or obligation: this is when official people (public officials) have duties to take action to protect your rights

Privacy: this is about the information you want to keep secret, and having your own space

Proportionate: everything else should be tried and the least restrictive thing should be chosen

Public officials: these are the people working in public services. They have human rights duties

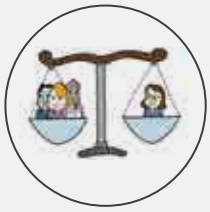
Safety: this is about you feeling safe and not feeling threatened or neglected

What are human rights?

Human rights are our basic freedoms. Human rights make sure people are...

Treated with dignity.

Treated with respect.



Treated fairly.

Listened to and **have a say** over their lives.

Human rights make sure you are **involved in the decisions** that are made about your care and treatment.

Human rights are **not gifts** from the government or rewards that you earn.

They are the **basic rights everyone can expect.**

Terrible things happened to people in World War II.

To try and stop these things happening again, after the war all the governments in the world came together to agree a **set of rules**.

These rules protect our human rights. They **tell governments how people should be treated.**

Who has human rights?

Every person has human rights.

Everybody has the same human rights.

Everybody who has a learning disability and / or autism has human rights.

How are my rights protected?

The Human Rights Act is the main way your human rights are protected in the UK.

The Human Rights Act contains a list of 16 rights (called 'Articles'). These rights are listed on the back page of this booklet.

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

one

The Human Rights Act puts a legal duty on public authorities and officials to respect and protect your rights in everything that they do.

You don't need a lawyer to use the Human Rights Act. You can raise the issue about your care or treatment directly with service providers. We explain this in more detail on page 14.

two

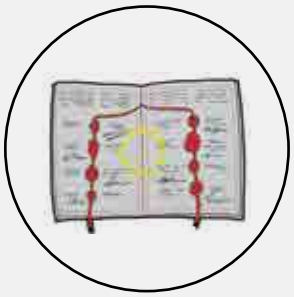
All other laws should respect your human rights.

For example, if you are worried about how a part of the Mental Health Act is affecting your human rights, you can ask a court to look at this.

In real life: Sally is in a long-term relationship with another woman. She was diagnosed with paranoid schizophrenia and depression. Sally didn't get on with her mother and didn't see her.

Sally's local authority made her mother her "nearest relative", not her partner. Sally challenged this in court and it was decided that the word "relative" under the Mental Health Act should include same sex partners

(R (SG) v Liverpool City Council, 2002. We made up the name).



three

The rights in the Human Rights Act are taken from the European Convention on Human Rights.

The UK helped write the Convention.

Before we had the Human Rights Act in the UK, you had to go to the European Court of Human Rights (in France) to get help. This is far away and it can take years to get your case heard.

So the Human Rights Act brought these rights closer to home.

This means you can now ask your local court or tribunal to help you with your rights.

Who has duties to uphold my human rights?

Who

Public authorities have a legal duty to respect and protect your rights in everything that they do, including the services you use.

This means that **people working in public services**, called **public officials, have to uphold your human rights**.

This includes:

NHS staff

Local authority staff e.g. social services, housing etc

Private health and care providers where your care is arranged or paid for (in any part) by the local authority

Police

Prison staff

Courts and tribunals, eg the Mental Health Tribunal or the Court of Protection

This is not a full list, just examples of who has duties to uphold your rights.

Sometimes a local authority will pay a private company or a charity to deliver health and care services.

These organisations and the people working for them also have a legal duty to uphold your rights.

If you don't think your human rights are being respected you should contact someone working in a public authority like a social worker, your GP, your council or the Care Quality Commission.

Once they know your rights are at risk, they will have a duty to act and take steps to protect your rights.

For serious concerns, contact the police.

Why are human rights duties important?

Who

This duty is really important in everyday situations because if you are treated badly by services you can:

Speak up because you have human rights which should be respected and protected

Talk to your services about whether they are meeting their legal duty to respect and protect your human rights

Work with services to find better solutions without the need to go to court or use a lawyer

What rights do I have?

There are 16 rights in the Human Rights Act – a full list is on the back page of this booklet.

The rights in the Human Rights Act are called 'Articles'.

In this part of the booklet we explain some of your human rights.

These are the ones which will usually be important in health and care services that you may use:

Right to life

Right to be free from inhuman and degrading treatment

Right to liberty

Right to respect for private and family life, home and correspondence

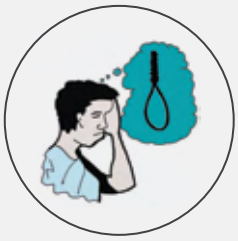
Right not to be discriminated against when relying on your other rights in the Human Rights Act

Right to life

This right is protected by Article 2 in the Human Rights Act.

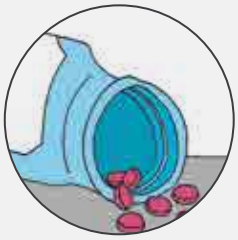
How is my right to life relevant to me when using health and social care services?

Some examples include:



If you are having **suicidal thoughts** or want to take your own life whilst in hospital or in detention and public officials know you are at risk of suicide but don't protect you

Abuse or neglect in detention or care which leads to death



Healthcare professionals **refusing to give you life-saving treatment** because you are living with learning disabilities and / or autism

Can my right to life be restricted by health and care services?

No. A health or care professional cannot deliberately take away your right to life.

What duties do health and care workers have about my right to life?

To RESPECT your right

This means not deliberately taking away your life.

To PROTECT your right

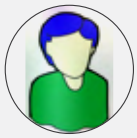
This means taking reasonable steps to protect your life when public officials know (or should know) that your life is at real and immediate risk.

This risk could be from another person, or from yourself (if you have suicidal thoughts whilst in the care of services).

To FULFIL your right

This means investigating when officials may have been involved in a death or failed to act, for example if a person staying in a residential care home takes their life.

In real life: Right to life



Life

GP has to arrange treatment for a man living with learning disabilities

Bryn is 60 years old and lives in supported living. Bryn has complex learning disabilities and people can find it really difficult to understand what Bryn is telling them.

Staff noticed that Bryn started sitting in his chair to go to sleep. They were worried that he might have problems with his heart, so they called in Bryn's doctor.

They had a meeting with the people involved with Bryn's care to work out what needed to be done. At this meeting Bryn's doctor said because Bryn had a learning disability and had no quality of life he would not organise a heart scan for Bryn.

Bryn's Mental Capacity Advocate was also at this meeting. She had been to a workshop on human rights run by the British Institute of Human Rights. She didn't think that Bryn's rights were being respected. She knew that Bryn had:

- **the right to life (protected by Article 2 in the Human Rights Act)**
- **the right to be free from discrimination (protected by Article 14 in the Human Rights Act)**

At the meeting Bryn's advocate asked the doctor if he would have arranged a heart scan if anyone else in the room was in this situation. The doctor said he would. The people at the meeting then agreed that Bryn should get his scan.

The advocate had to keep asking the doctor to organise the scan and eventually it was arranged for Bryn to have a heart scan. However, it had taken so long to organise it was too late to treat his heart condition and sadly Bryn died.

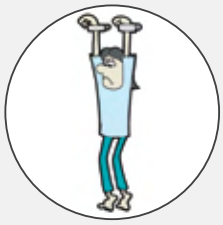
(Example from Solent Mind, participants in BIHR's project Care and Support: A Human Rights Approach to Advocacy)

Right to be free from inhuman or degrading treatment

This right is protected by Article 3 in the Human Rights Act.

How is my right to be free from inhuman and degrading treatment relevant to me when using health and care services?

This right protects against very serious harm, including abuse or neglect, such as:



Use of **excessive force** to restrain you

Physical or mental **abuse**

Lack of care or medication leading to extreme or long periods of pain or suffering

Leaving you in your own **bodily waste** for long periods

Not getting enough to eat or drink to keep you well

Can my right to be free from inhuman and degrading treatment be restricted by health and care services?

No. This right is called an **'absolute right'**. This means that public officials must not treat you in an inhuman or degrading way.

When is treatment 'inhumane or degrading'?

This is treatment which:

Makes you very frightened or worried

Causes you a lot of pain

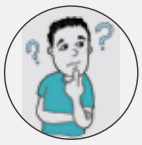
Makes you feel worthless or hopeless

This right stops you being treated like this.

To use the Human Rights Act to protect you against inhuman or degrading treatment, it must be very serious.

Because everybody is different, what is inhuman and degrading treatment for one person might not be inhuman and degrading for another person. It all depends on each person and how treatment affects them.

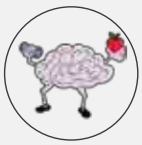
So, public officials must think about things like:



What you are able to understand,

Your age,

Whether you are a man or a woman,



How you are feeling mentally,

How long your treatment has been going on or will go on.

This will help decide how serious your situation is and if your treatment is 'inhuman and degrading'.

Less severe abuse, which has a less serious impact on you, is protected by your right to respect for private life – more information on this is on page 31.

This right also protects against torture.

'Torture' is a word people may use to describe bad treatment. But under the law, torture means something very specific and is about someone like a police officer deliberately causing serious physical or mental suffering to a person for a reason (such as getting information out of the person).

This would very rarely apply to health and care services.

What duties do health and care workers have about my right to be free from inhuman and degrading treatment?

To RESPECT your right

This means not treating you in an inhuman or degrading way.

To PROTECT your right

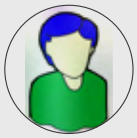
This means if public officials know (or should know) that you are at real risk of inhuman or degrading treatment, they try to protect you.

This risk could be from another public official or other people like your family or a patient, or from yourself (if you are at risk of self-harm whilst in the care of services).

To FULFIL your right

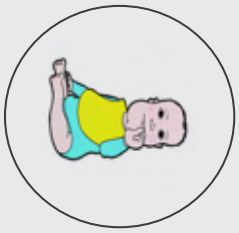
This means investigating when officials may have been involved in inhuman or degrading treatment or failed to act to prevent such treatment whilst you are in the care of services.

In real life: Right to be free from inhuman or degrading treatment

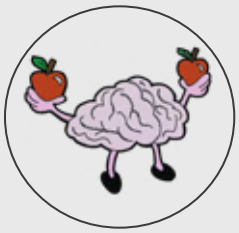


Hospital has to investigate treatment of woman with learning disabilities

Susan was an older woman with learning disabilities. She had a fall and was taken into hospital.



Susan had a doll which she loved and took it with her into hospital. Susan's family found the doll on the floor of the hospital broken.



Susan was very upset because her doll was very important to her. It being broken really hurt Susan's mental health. Susan's family believed the doll was damaged deliberately to punish Susan for not doing as she was told.

The hospital offered to replace the doll, but they would not apologise and would not investigate what had happened. Susan's family contacted lawyers who helped her argue that her treatment was inhuman and degrading.

This was settled out of court and the hospital made a financial award to enable Susan to move out of the hospital and help her continue her life. The hospital also agreed to investigate the incident to make sure it did not happen to anybody else.

(Real-life example)

What is capacity?

Capacity is about your everyday ability to make decisions.

This includes making decisions about your care and treatment.

The Mental Capacity Act is a law which has a legal test to check this.

A number of things can affect your capacity such as mental illness, learning disability, dementia, brain damage or if you have taken drugs or drank too much alcohol.

The public official will have to assess if you are able to:

Understand

Remember

Weigh up the pros and cons of your choices

Let people know your decisions

Capacity is 'task-specific'. This means:

- It focusses on the decision that needs to be made at the time. A public official should first think that you do have capacity to make a decision. If they are not sure they need to do an assessment.
- If your incapacity is temporary (for example if it's due to being drunk) you can ask officials to wait until you are able to make a decision.
- If you lack capacity to make one decision it doesn't mean that you lack capacity to make other decisions
- Capacity can also change, so things need to be kept under review and your capacity re-assessed later on.

Capacity: What about my human rights?

A public official should first think that you do have capacity to make a decision and, if they are not sure, they should do an assessment.

This is because of your human rights.

If it is decided that you do not have capacity to make a decision, a public official will make the decision for you. That person must make the decision in your best interest. This means the decision must be what is best for you, not for anyone else.

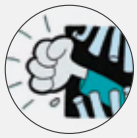
They should:

Think about your human rights

Consider your wishes and feelings

Support you to be involved in decisions as much as possible.

Right to liberty



This right is protected by Article 5 in the Human Rights Act

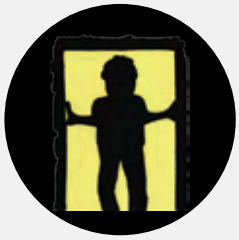
How is my right to liberty relevant when using health and care services?

Some examples include:

Being **restrained** for long periods

Being kept somewhere that isn't right for you because of lack of space e.g. being sent to prison when a court hasn't ordered that you serve a prison sentence

Significant **delays or cancellations of hearings** allowing you to challenge your detention



Being told you are not allowed to leave or being stopped from leaving a place (like a care home or hospital)

Sometimes you can be detained. This would be done through the Mental Health Act or the Mental Capacity Act. We tell you more about this on the next page

Can my right to liberty be restricted by health and care services?

Yes. Your right to liberty can be limited where necessary.

Here are 2 examples:

1. If you have been **detained under the Mental Health Act.**

This can only be used if:

You have a recognised 'mental disorder'

AND

Your detention is necessary to keep you or other people safe.

The authority detaining you would need to be able to prove this.

2. If you have been assessed as lacking capacity

That means you are unable to make a decision or unable to agree to treatment for a mental health issue.

It may be you are living somewhere that people think you may be in danger or at risk and you are unable to make a decision about leaving. **To keep you safe your right to liberty may need to be restricted.**

Before this can happen there is a formal process that needs to be followed by those providing your care.

This is called a **'Deprivation of Liberty Authorisation'**. There is more information about this on the next page.

Mental capacity and restricting your liberty

The 'Deprivation of Liberty Safeguards' (DOLS) are part of the Mental Capacity Act.

In the past, people who couldn't understand what was happening to them (people who had mental capacity issues) sometimes didn't have their human rights protected.

To stop this happening, a set of laws were made in the Mental Capacity Act called the Deprivation of Liberty Safeguards, or DOLS for short.

DOLS are a set of rules that must be followed to protect your rights if you are in hospital or in a care home.

These are called safeguards and are there to protect you.

These safeguards make sure your freedom is only restricted when it is really necessary.

What duties do public officials have about my right to liberty?

To RESPECT your right

This means they must not do extreme things to stop you moving (such as being locked in a room or being strapped to a chair) unless it is absolutely necessary and they can give good reason why you need to be stopped.

To FULFIL your right

There are lots of safeguards which apply if your right to liberty is restricted.

These safeguards are set out in Article 5 of the Human Rights Act and include:

- You must be able to challenge the restriction of your liberty through an independent court or tribunal (in England you can do this through a Mental Health Tribunal for mental health issues or the Court of Protection for mental capacity issues)

- This review of your detention must be carried out 'speedily' and delays or cancellations of hearings can be challenged using your right to liberty

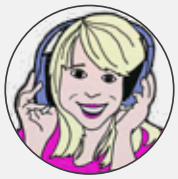
- You must have a chance to have your side of the story heard at the hearing, either by you or your representative

- You have a right to a lawyer to advise and represent you at the hearing

- You must have chance to see and challenge a report about you or any other evidence about the decision to restrict your liberty.

In real life: Right to liberty

Preventing people with mental capacity issues from leaving services



Meg was 17 years old. Meg had a learning disability and sometimes behaved in a way some people found difficult.

She had been living with her mum. People were worried that there was abuse, so **Meg was moved to an NHS residential unit.**

Meg had staff with her whenever she left the unit.

The court was asked to decide whether Meg's right to liberty was being restricted.

The court said **everyone** has human rights and **the right to liberty applies to people with a learning disability in the same way.**

The court decided that Meg's right to liberty was being restricted because she was not allowed to leave on her own and was always controlled by staff.

When things like Meg's story happen a 'Deprivation of Liberty Authorisation' needs to be made so that checks and safeguards are put in place to make sure the restriction of liberty is necessary and justified.

(P and Q v Surrey County Council, 2014, better known as the 'Cheshire West Case'. We made up the name.)

Right to respect for private and family life, home and correspondence

This right is protected by Article 8 in the Human Rights Act.

An important part of this right is making sure your choices are respected. This right will be relevant to your life in lots of ways.

There are four parts, which are each explained below.

How is my right to respect for private life relevant when using health and care services?

Some examples of what this right protects:

Your **private information.** This includes keeping your personal information confidential.

You having **control** over your own body and life.

You **being asked** about decisions about your care and treatment. This is sometimes called having **autonomy**. This also includes agreeing or consenting to medical treatment (except if you are detained under the Mental Health Act and the hospital can show there is a 'medical necessity' for the treatment).

Your **wellbeing**, which means being free from abuse or neglect.

You **being part of your community,** if you want to.

Choice

How is my right to respect for **family life** relevant when using health and care services?

Some examples of what this right protects:

Making **friends**, finding a **partner** and having a **family**.

Keeping in touch with your family.

How is my right to respect for **home** relevant when using health and care services?

This is not a right to housing, but a right to respect for the home that you already have.

Some examples of what this right protects:

Living in a place you call home. This could be a place where you have lived a while and have friends there, like a care home or hospital ward.

Being removed from somewhere you live to receive health or care when you've been promised it is your 'home for life', for example if your care home is being closed.

How is my right to respect for **correspondence** relevant when using health and care services?

Some examples of what this right protects:

Being able to **keep in touch with people** (including by letter, email etc.)

Keeping correspondence private (these are things like letters and emails).

Sometimes, if you are detained (see page 29) the people providing your care may be able to check or keep your correspondence. This is because of the Mental Health Act.

Before they do this, there is a test they must follow to make sure your human rights are respected. We explain this in the next section.

Can my right to private and family life, home and correspondence be restricted by health and care services?

Yes. But there is a test the people who provide your care must go through if they need to restrict your right.

They must be able to show that it is:

1. Lawful

There must be a law which allows public officials to take that action (such as the Mental Health Act or Mental Capacity Act).

2. Legitimate

There must be a good reason (for example public safety or protecting the rights of other people, including other patients/residents and staff).

3. Necessary

Public officials, like health and care workers, must have thought about other things they could do, but there is no other way to protect you or other people. This means the action taken must be proportionate. This means that all the different options available should be considered and officials should pick the one which is least restrictive.

Public officials that want to restrict this right must show they have met all these tests.

The people providing your care must be able to show all three stages of this test are met.

What duties do health and care workers have about my right to private and family life, home and correspondence?

To RESPECT your right

This means only doing things when they NEED to.

To PROTECT your right

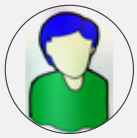
This means doing things to protect you or other people and making sure you are involved in decisions about your care.

The legal term for this is a ‘positive obligation’.

To FULFIL your right

This means that when decisions are made about your care you are treated fairly.

In real life: Right to respect for private life



Privacy for couple living with learning disabilities in residential unit

Tim and Sylvia were a couple who both had a learning disability. **They had a young child**.

Social services placed them in a residential unit for a short time so that could check how they were looking after their child.

There were **CCTV cameras in their rooms**, including in their bedroom, even though the baby slept in a separate nursery.

Tim and Sylvia were unhappy about the CCTV cameras. They talked to social services about their right to respect for private and family life.

After the discussion, **social services agreed to turn the cameras off in their bedroom at night time.**

(Real-life example taken from BIHR's booklet 'The Human Rights Act: Changing Lives'. We changed the names.)

Choice

In real life: Right to respect for family life

Young man living with a learning disability returned home to live with father

Steven is a young man with a complex learning disability. He lived at home with his dad. When his dad was ill Steven went for a short break at the local authority support unit.

The local authority kept Steven there for over a year. He and his dad didn't want this.

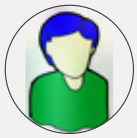
When Steven tried to leave, the local authority signed a Deprivation of Liberty Authorisation. They wanted Steven to stay in a care home miles away from his father.

Steven and his dad took a human rights case to the courts to challenge this. **The court decided that the local authority hadn't protected Steven and his dad's right to family life.** It also decided that Steven's right to liberty had been breached.

This was because the Deprivation of Liberty assessment **had not asked what Steven and his dad wanted and it had taken too long.**

(Hillingdon London Borough Council v Neary, 2011)

In real life: Right to respect for home life



Teenager and his family receive further support from local authority

Daniel is 13 years old and lives with his mum Mrs Smith. Daniel has Down's syndrome, and **when he gets upset he sometimes hurts himself**. Mrs Smith tried to get some extra support, but the local authority refused.

She got really worried about Daniel because he was stuck in the house. She was afraid that Daniel would badly hurt himself or another member of the family.

The Down's Syndrome Association had been working with the British Institute of Human Rights to look at how the Human Rights Act could help families like Daniel's get the right support.

The Down's Syndrome Association **wrote to the local authority. They explained how Daniel and his mum had the right for private and family life (Article 8)**. They also told the local authority that it was the local authority's duty to provide the support for this to happen.

Daniel's respite care was soon increased and the local authority worked with the family to see what else could be done to help. Now, **Daniel has lots more to do and is much happier**. His behaviour is getting better too. He and his family are able to enjoy the time they spend together again.

(Down's Syndrome Association example)

Choice

In real life: Right to respect for correspondence

Young people's hospital changes policy on mobile phones and internet using human rights

The St Aubyn Centre is a unit that looks after young people with mental health issues. **Staff were worried about the young people who stayed there using the internet.**

Staff were afraid that the young people may use websites that were risky and that they wouldn't be safe. **The staff decided to ban mobile phones and the internet from the unit.**

The young people who stayed at St Aubyn's were away from their family and friends for many weeks or longer. After working with the British Institute of Human Rights, staff realised that the ban could interfere with young people's right to correspondence.

St Aubyn Centre reviewed their policy on mobile phones and the internet. Now all the young people are allowed mobile phones and access to the internet. If there are concerns about their safety then the staff will talk it over with the person.

This means the young people can keep in contact with friends and family.

It has also helped staff at St Aubyn Centre to have a clear idea about **how to respect rights and uphold their duties to protect them.**

(Example from St Aubyn Centre, BIHR partner on Delivering Compassionate Care: Connecting Human Rights to the Frontline)

Right to be free from discrimination

This right is protected by Article 14 in the Human Rights Act.

This is not a right to equality or a stand-alone right to be free from discrimination.

It means when you are using the Human Rights Act, you should be treated the same as everyone else.

If you think you are being treated differently you can bring this up when using your other rights in the Human Rights Act.

For example, if a doctor makes a decision about not treating your physical health problem because you are a person living with autism, your right to wellbeing under Article 8 would be engaged and you can use non-discrimination arguments in your negotiations with the doctor.

Equality

How is my right to be free from discrimination relevant when using health and care services?

Some examples of what this right protects:

Public officials deciding not to treat your physical health problem because you're a person living with learning disabilities and / or autism

Getting worse care than other patients because you're a person living with learning disabilities and / or autism

Public officials deciding you should live in an institution like a hospital or unit, just because you're a person living with learning disabilities and / or autism

Bullying or harassment

Can my right to be free from discrimination be restricted by health and social care services?

Yes, sometimes. **Not all discrimination is against the law.**

Sometimes you may be treated differently, but this is not discrimination. There may be a good reason for it.

For example, if a local authority is running a service for people living with learning disabilities, this would be treating them differently because of their disability. The good reason would be that this service is needed by people with learning disabilities.

Very strong reasons are needed to justify different treatment because of disability.

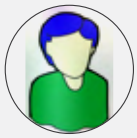
How might I be discriminated against on the basis of being a person living with learning disabilities and / or autism?

If you are **being treated less favourably** than other people in the same situation based on your learning disabilities and / or autism.

Failing to treat you differently when you are in a very different situation to others, for example because of your learning disabilities and / or autism.

Applying rules to you that have a worse impact on you because of your learning disabilities and / or autism.

In real life: Right to be free from discrimination



Man living with learning disabilities challenges 'Do Not Resuscitate' order

Andrew was a 51-year old man with Down's syndrome and dementia.

During a hospital stay he had a 'Do Not Resuscitate' order put on his file without him or his family being consulted. 'Do Not Resuscitate' is an instruction to the medical team not to give medical treatment if he fell unconscious. This means he would not be given life-saving treatment if he needed it.

The reasons written on the order by the doctor were: "Down's syndrome, unable to swallow... bed bound, learning difficulties".

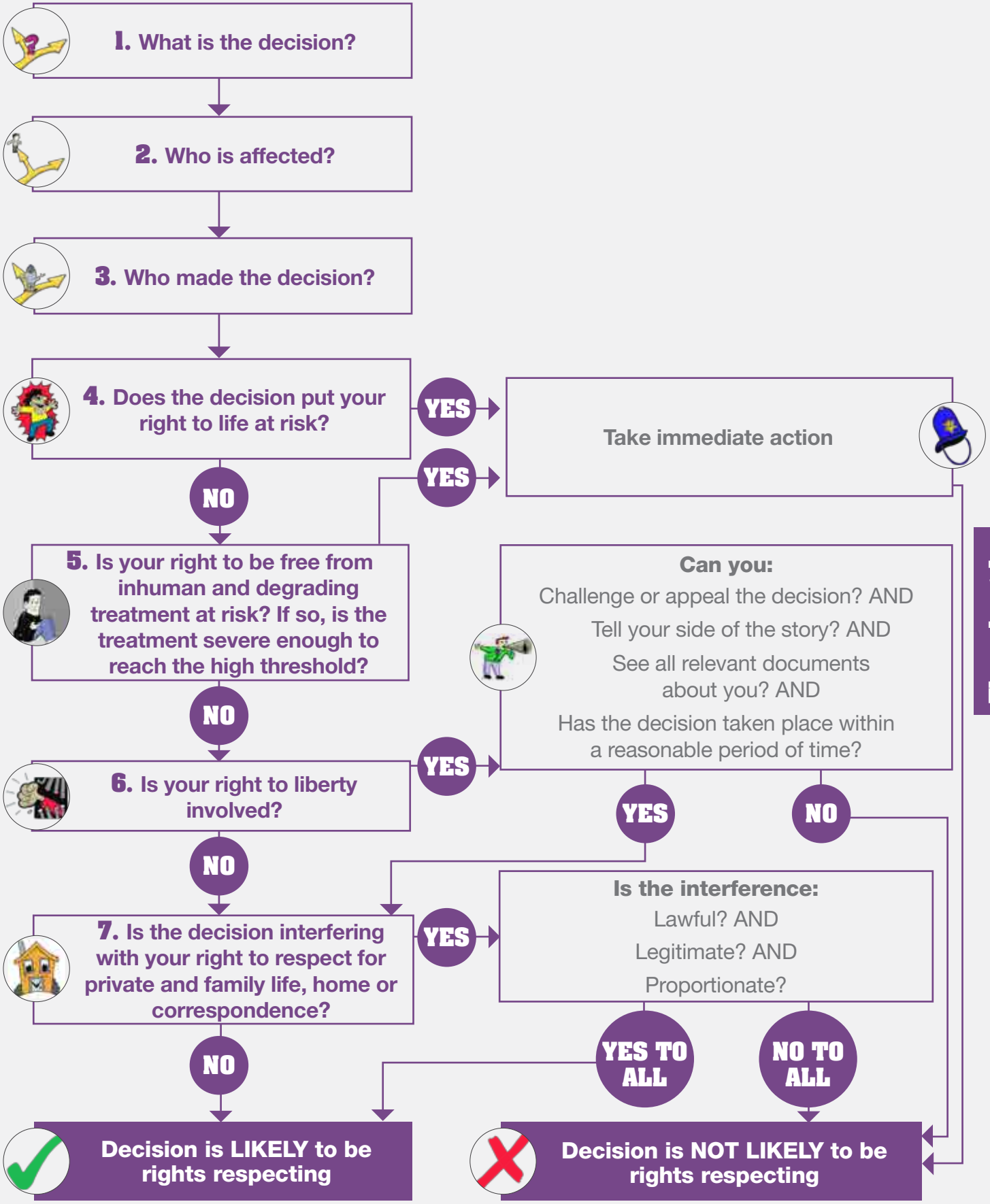
As his life was at stake he was able to challenge this as discrimination joined to his right to life.

He started a human rights legal case but it was settled out of court and the NHS Trust apologised.

(Real-life example)

Equality

Using human rights: is my issue about human rights?



Flowchart 1

Is my issue about human rights? Explaining the flowchart steps

Step 1 What is the issue/ decision?

What happened, when and where?

Be clear about what has happened.

Be clear about what it is you want to say has been done wrong.

Is it the way you have been treated?

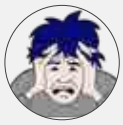
Has someone made a decision that affects you?

Is it a decision that affects other people too?

Step 2 Who has it affected and how?

Are other people affected?

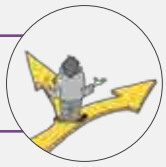
How has it affected you?

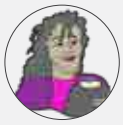


Think about your age, health, if you are a man or woman…

How has it made your life worse?

Step 3 Who has made the decision?





Public authorities, like health and social care workers, have a legal duty to protect your rights.

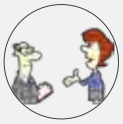
Private companies and charities who are paid by the local authority to give you a service have a legal duty to protect your rights.

Sometimes other people try to stop your rights, like family members or neighbours. They don't have a legal duty to protect your rights. But, if you tell a public official, like a social worker or police officer, they must take steps to protect you.

Step 4 Does the decision put your life at risk?

Is your life at risk? Call the police on 999

Has a public official made a decision about your care or treatment which puts your life at risk?



You should say something straight away to the public authority. They have a duty to protect you.

Is your right to life at risk from another person, like a member of your family or a patient?

You should let a public official know about this as soon as possible. They have a duty to protect you.

Step 5 Is your right to be free from inhuman and degrading treatment at risk?

This is an **'absolute right'**. This means that it must always happen and no one can stop this right.

This right is to stop you being abused or neglected.

You will need to show that what has been done to you is very serious (see page 19 for more information).

It is important to remember that most of the other rights in the Human Rights Act are **'non-absolute'**. This means they can be restricted to keep you or others safe.

Is my issue about human rights? Explaining the flowchart steps

Step 6 Is the right to liberty involved?

Being detained means being kept somewhere and being stopped from leaving.

This might not be against the law if there are serious reasons.

These reasons are explained in the Human Rights Act (see step 6 in the flowchart)

If staff say you are not allowed to leave a care home or hospital or stop you from leaving, your right to liberty may be at risk.

Staff need to follow some rules if they want to stop you leaving.

These rules are called the 'Deprivation of Liberty Safeguards'.

Step 7 Is your right to respect for private or family life, home or correspondence being restricted?

If a public official want to restrict your rights they must make sure:

It is lawful - that they follow the law,

It is legitimate - that they have a very good reason

and that it is **proportionate** – that you are being treated fairly.

See page 34 for more information.

There are other human rights which can be restricted.

These include:

Right to freedom of expression – saying what you want

Right to freedom of assembly and association – getting together with other people

Freedom of thought, conscience and religion – Having your own beliefs and telling people about them

The same rules apply when these rights are stopped.

If you have a complaint about your human rights you need to get lots of evidence.

Think about how your human rights have been affected.

What if it is not a human rights issue?

If you have followed the flowchart and it's not a human rights issue you can still think about:

Are you being discriminated against? Are you being treated differently because you have a disability?

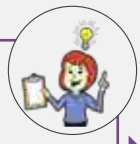
Does the decision break the Equality Act? You may need to get some advice.

See Page 54 for more information.

Things may change and you may need to use the flowchart again in the future.

Flowchart: What to do if your issue is about human rights...

This flowchart gives you information and tips about how to take action and raise human rights concerns.



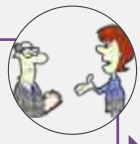
Step 1

Identify the issue

Are you in immediate danger?

Yes, I need help quickly

No, move to step 2

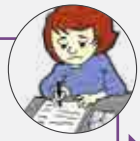


Step 2

Talk to a public official

They agree. Work together to sort things out

That doesn't work, move to step 3



Step 3

Make it formal: write a letter

They agree. Work together to sort things out

That doesn't work, move to step 4

Step 4

Step up your action

They agree. Work together to sort things out

That doesn't work, move to step 5

Step 5

Take further action such as...

Follow the 'Internal Complaints Procedure'

Contact The Ombudsman(s)

Contact the Care Quality Commission or Healthwatch

Seek legal advice

Flowchart 2

What to do if your issue is about human rights... Explaining the flowchart steps

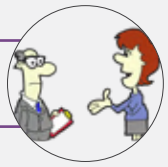
Step 1 Identifying the issue

This is what the first flowchart on page 43 helps you to do.

If you are in danger - call the police immediately on 999.

Also see the '**Where can I get more help?**' section on page 69.

Step 2 Talk to a public official



You could ask to have a meeting to talk about your complaint.

Step 3 Make it formal: write a letter

If you can't fix the problem by talking to people, you could write a letter of complaint.

You should get a reply in a reasonable time.

What if they don't respond?

Check to see if they received the letter by phoning them.

If they have not received it send it again and send a copy of your letter to the person in charge.

You could send it by registered post or deliver it by hand.

You could tell the first person you wrote to that that you have written to their manager.

This might make them hurry up!

Step 4 Step up your action

There are a number of different ways you could step up your action, including:

Write to them again.

Explain that you know your human rights.
Tell them what those rights are.

Tell them what they **MUST** do to protect your rights.

Tell them how you think the problem can be fixed.

Ask for a meeting, now.

Warn them that you will take further action.

What if you receive a response which you don't agree with?

You could ask them to tell you why they made their decision.

Do this with any meetings you have or letters you receive.

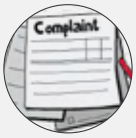
This may help them to think again and will help you to work out the best thing to do next.

Step 5 Take further action

There are four things you can do if you are still not happy.

Someone can help you.

But, be clear what YOU want to happen.



Follow the Internal Complaints Procedure

There is a single way to make a complaint for all health and adult social services in England.

This includes complaints about the local authority, NHS hospitals and support providers.

You can make the complaint or your advocate can do it for you.

If this doesn't work...

The Health Service Ombudsman looks at complaints about health services.

The Local Government Ombudsman looks at social care.

If your complaint is about the NHS AND Social Care, both will look at the complaint.

The Ombudsman is independent of the NHS, local authorities and Government.

They do not have to look into every complaint and they will usually ask people to use the Internal Complaints Procedure first.

Step 5 Take further action

If the Internal Complaints Procedure and Ombudsman don't solve the issue, you can always contact the Care Quality Commission or Healthwatch

The Care Quality Commission

The Care Quality Commission (CQC) is an independent organisation which makes sure health and social care services in England are providing a good service and are meeting the national standards. This includes human rights.

They also check the use of the Mental Health Act. **It has a duty to protect people.**

Especially people who:

- are, or have been detained in hospital
- are subject to Community Treatment Orders
- are subject to guardianship

Anyone can make a complaint to the CQC about how the Mental Health Act is being used including staff, patients and the public.

Healthwatch England

Healthwatch England is an independent body. They try to be the 'patient voice' in health and social care. They can write to an organisation if there is a problem and the organisation must listen.

Healthwatch England can also visit social care services to see what is happening. These visits are called 'enter and view'. After an 'enter and view' visit, if they are not happy with what they see **they can ask CQC to take action.**

You can raise your concerns with your Local Healthwatch (See page 69 for more information).

Flowchart 2

Step 5 Take further action

Another thing you could do is get legal advice

Many complaints get sorted out without going to court.

But sometimes a court case will be the only way to get your problem fixed.

If you think this may be the only way, get legal advice.

Going to court or getting legal advice or using a solicitor usually costs money. You can contact the Legal Aid Agency for more information about costs.

See Page 69 for more information.

Other places you might find support to help with legal advice and going to court:

- Trade Unions
- University Law Clinics
- Pro Bono Law Centres
- your local Law Centre
- your local Citizen's Advice Bureau

What the courts can do if you take a human rights case:

The Human Rights Act says that a person whose human rights have been stopped must be provided with a remedy that is necessary, just and appropriate.

This means that things must be made right for the person.

The court can tell an organisation (like a local authority) that what it did was wrong.

The court can order an organisation to do something or stop doing something.

The court can make the organisation pay a person money to make up for the things they have gone through.

If you are worried about how a part of law, such as the Mental Health Act or Mental Capacity Act, is affecting your human rights, you can ask the higher courts to look at this.

They can decide whether a law needs to be changed.

If they do they will issue what is called a **'Declaration of Incompatibility'**.

The Government must then decide whether to change the law.

Flowchart 2

Example 1: Responding to behaviours of concern – worked example

Erik is a 26 year old man with learning disabilities. He lives in a 24 hours supported housing unit which is paid for by his local authority. Every morning Erik goes for a walk with his care worker, Paula. They go the same way every day to a local café. Erik really enjoys his walk.

Over the past few weeks, Erik has run away from Paula. **Paula is worried that Erik will get hurt** if he gets lost in the busy town centre.

Paula has decided to go a different way into town with Erik in case he runs away again.

No one has talked to Erik about changing his route.

Erik doesn't like change and gets upset. He starts acting differently when he is out in town and when he is in the care home. Paula finds Erik's behaviour difficult and the pair do not get on as well.

Erik is told that if he doesn't behave he may not get support to go for a walk everyday.

Step 1 What is the decision?

The decision is to change Erik's routine to keep him safe in case he runs away. **No one has talked to Erik about this change.** His human rights may be at risk.

Step 2 Who does it affect?

Erik is affected most.

To know how badly this has affected Erik we need to think about:

- How much does Erik understand?
- How long has Erik been walking the same route?
- Erik's behaviour has changed a lot since this happened. He is not happy.

- Who is else is affected? Other people living in the care home? Paula? Other staff?

Step 3 Who has made the decision?

Paula, Erik's care worker. Erik's care is paid for by the local authority, so the housing support unit must protect his human rights.

Step 4 Does the decision put Erik's right to life at risk?

No. But is Erik in danger if he runs away? Are there roadworks or fast cars? Can Erik cross the road alone? We would need more information.

Example 1

Step 5 Is Erik's right to be free from inhuman and degrading treatment at risk?

No. Even though Erik is very unhappy, changing route is not serious enough to be called inhuman or degrading. We need to think about Erik's other rights too.

Step 6 Is Erik's right to liberty at risk?

No. Erik is allowed to leave the unit. However, threatening to stop his daily walk may put his right to liberty at risk.

Step 7 Is the decision interfering with Erik's right to respect for private and family life, home and correspondence?

Yes. Changing the route stops Erik being in control of his own life and going where he wants. To stop Erik the care workers must show the decision is:

Lawful:
workers would need use the Mental Capacity Act. They would need an assessment to show that Erik is not able to make the decision. Then they would need to get a **'Deprivation of Liberty Authorisation'** See page 28.

This has not happened.

Legitimate:
What was the good reason? To keep Erik safe. However, Erik is now so unhappy he may hurt himself or other people.

Proportionate:
Is the decision too harsh? Paula changed the route to walk down quieter streets. Paula thinks this will stop Erik running away.
But this is making Erik very unhappy and making his behaviour worse.
Maybe the staff could have thought about other options.

Answer to the question: Is it a human rights issue?

Yes. The decision stops Erik having control over this life.

This may restrict Erik's right to respect for private life.

This may not be legal.

The staff should have thought about other things to try.

The decision should be challenged.

So what can you do if you have a human rights issue?

On the next pages we work through the flowchart: what to do if your issue is about human rights…

Example 1

Working through the flowchart: what to do if your issue is about human rights...

Step 1 Identify the issue

By using our flow chart we found that this was a human rights issue.

We found that the decision of staff to change Erik's routine, without including him, restricts Erik's right to respect for private life.

We found that staff had not met all the tests.

Step 2 Raise the issue informally with the public official: ask for a meeting

Erik could ask for a meeting to talk to staff and tell them why he is unhappy.

He can have support to do this from friends, family, or an independent advocate.

A support worker at his housing unit could speak up for him.

Step 3 Raise the issue formally: write a letter

Erik (or someone supporting him) could write a formal letter to the management of his housing unit if a meeting doesn't work.

You can see an example letter on the next page.

Example 1

Example Letter

Housing Unit
Manager
Rose Avenue
Oldtown, O1 B11

O1 February 2017

Dear Mrs Bloggs,

I am representing Mr Erik Schwartz who is a resident at your housing unit. A recent change in routine has caused considerable distress to Mr Schwartz. Staff have decided to change Mr Schwartz's route on a walk they support him to take each day, which usually goes through the town centre. Staff have not discussed this change with Mr Schwartz to explain why they want to do this or to find out his wishes and views. The distress this has caused has led to incidents of concern between Mr Schwartz and the staff, and that the situation has got worse, and not better as the decision had intended.

As care is arranged by the local authority, you have a legal duty under the Human Rights Act to respect and protect his rights. This change in routine is interfering with his right to respect for private and family life (Article 8 in the Human Rights Act).

Although I appreciate your commitment to maintaining the safety of Mr Schwartz, the Human Rights Act requires you to make sure that any decision that interferes with his right to respect for private and family life is lawful. As Mr Schwartz's capacity to make decisions about his daily routine or walk have not been raised before, and he is not subject to a Deprivation of Liberty order, I am concerned about the legal basis for the decision to override his autonomy. I am also concerned that the decision does not meet the proportionality test. Perhaps you could think about another way to keep him safe and not interfere with his right as much? Mr Schwartz should be involved discussions about his routine to discuss possible risks and how to manage these. For example, could you change the time slightly but keep the same route so that it is at a quieter time?

If staff spoke to myself or Mr Schwartz about the decision maybe we can find a better solution that doesn't cause so much distress to him, and reduces incidents of concern in his behaviour.

I would be grateful if you could please respond to my letter within the next two weeks of the date above. I am sure that we can resolve this issue amicably, working with Mr Schwartz to protect his rights.

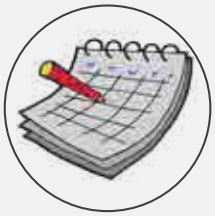
Yours sincerely,

Nick

What happened to Erik?

After they received this letter, the Housing Unit Manager (Mrs Bloggs) called for a meeting with Erik, Paula, Nick, and herself.

In the meeting Erik and Nick were able to talk about their concerns with the risk to Erik's human rights. Paula and Mrs Bloggs were also able to talk about their concerns with Erik's safety.



Together they worked out a plan that they were all happy with. It meant that Erik's route went back to the way it used to be, but they would go a little bit later than they used to.

Paula felt this would be safer for Erik. Erik was happy again.

Erik's behaviour got much better too.

The Housing Unit staff have started using human rights more when they make other decisions.

Example 2: Responding to breakdown of care arrangements – worked example

Gemma is in her late 40s and has a learning disability. Gemma had lived with her mum. When Gemma's mum died, **the Local Authority paid for Gemma to be looked after in a care home.**

The care home was for older people. It had locked doors to keep the people with dementia safe so they would not leave without support.

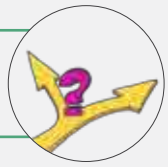
This meant Gemma could not come and go as she pleased as she had done when she stayed with her mum.

Gemma also paid money to the home for some activities, **but staff told her that she couldn't join in.** They told Gemma that the activities were for older people and not for her.

Gemma got very upset. Not only did she miss her mum, she was very unhappy not being able to come and go as she wanted.

Example 2: Responding to breakdown of care arrangements

Step 1 What is the decision?

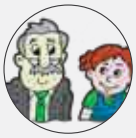


The decision is to move Gemma into a care home. The Local authority had to find somewhere for Gemma to live quickly because her mum had died. The care home was not the right place for Gemma.

Step 2 Who does it affect?

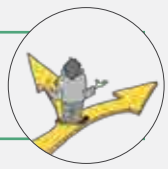
Gemma is most affected by the decision. Other people living in the care home may be affected too.

To know how badly this has affected Gemma, we need to think about:



- How old is Gemma? The care home is for much older people.
- Is she getting enough support after her mum died?
- Gemma used to be able to go out and about. Now she can't.
- Gemma is not allowed to take part in the social activities.
- Has Gemma told care home staff she is unhappy?
- What have the staff done to help?
- How are the other people feeling living with someone so much younger?

Step 3 Who has made the decision?



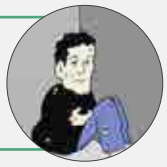
The local authority made the decision for Gemma to move into the care home.

Care home staff made the decision to stop Gemma joining in the social activities.

Step 4 Does the decision put Gemma's right to life at risk?

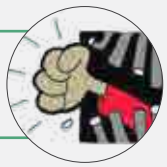
No. The decision does not put Gemma's right to life at risk.

Step 5 Is Gemma's right to be free from inhuman and degrading treatment at risk?



No. Even though Gemma is unhappy, living in the care home is not serious enough to be called inhuman or degrading. We need to think about Gemma's other rights too.

Step 6 Is Gemma's right to liberty at risk?



Yes. Gemma cannot come and go from the home freely. She used to be able to do this when she lived with her mother.

Gemma is not being detained under the Mental Health Act (or other mental capacity laws) and so she should be allowed to come and go freely. Gemma's right to liberty is at risk.

Her right to respect for private and family life is also likely to be at risk. This is because she is not able to take part in social activities and no longer has control over her money.

Answer to the question: Is it a human rights issue?

Yes.

The decision to place Gemma in a care home where the doors are locked restricts her right to liberty.

She has not been detained under the Mental Health Act and she has not been assessed as lacking capacity (See pages 24).

Example 2

Working through the flowchart: what to do if your issue is about human rights...

Step 1 Identify the issue

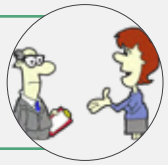
We found that it is a human rights issue.

It restricts Gemma's right to liberty, without being lawful, legitimate or proportionate.

To be lawful, Gemma would have to be detained under the Mental Health Act or assessed as not being able to make this decision.

This has not happened, so Gemma should be able to leave the home when she wants to.

Step 2 Raise the issue informally with the public official: ask for a meeting



Gemma could ask for a meeting to talk to staff and tell them why she is unhappy.

She can have support to do this from friends, family, or an independent advocate.

A support worker at the care home could speak up for her.

Step 3 Raise the issue formally: write a letter

To be lawful, Gemma would have to be detained under the Mental Health Act or assessed as not being able to make this decision.

You can see an example letter for a different story on pages 61.

Example 2

Working through the flowchart: what to do if your issue is about human rights...

Step 4 Step up your action

After following steps 1, 2 and 3, Gemma is still not happy. She should now step up her action.

Things she could do:

- Ask for another meeting

- Ask them to write down what they have done and why

Could she use her human rights more?

- Did she talk about the Human Rights Act?

- Did she tell the local authority what their duty was to protect her rights?

- Were there other ideas she could suggest?

Example 2

What happened to Gemma?

Step 5 Take further action

We see on page 52 - 54 the 4 different ways that people can take further action.

Gemma decided to telephone her local Healthwatch.

The Healthwatch staff she contacted had attended human rights training by the British Institute of Human Rights and recognised this as a human rights issue.

The Healthwatch staff arranged some 'Enter and View' visits to five local care homes.

They chose five because they didn't want to let people know it was about Gemma.

They talked to staff and people living in the homes about their human rights and if they were able to come and go as they wanted. This is part of their right to liberty.

The local Healthwatch wrote a report on each home.

In that report they said that the care home was not a good place for Gemma to live.

As a result, **the local authority now supports Gemma to live in her own flat.**

Gemma is much happier.

Example 2

Where can I get more help?

If you need some advice or support about your human rights, below are some organisations who can help with this:

Liberty

Human rights and civil liberties organisation Liberty run a public helpline for three afternoons a week. Contact them by phone or online.

www.yourrights.org.uk

0845 123 2307 020 3145 0461

Monday and Thursday 6.30 p.m. to 8.30 p.m, Wednesday 12.30 p.m. to 2.30 p.m.

Citizens Advice

Provides advice in person, over the phone and by web chat.

www.citizensadvice.org.uk

Find your local Citizens Advice

Advice: 03444 111 444 Text phone: 03444 111 445

Advice UK

This is not an advice giving organisation but has a directory of advice services. Find a service on their website.

www.adviceuk.org.uk

Local Healthwatch

Find your Local Healthwatch through Healthwatch England

www.healthwatch.co.uk/find-local-healthwatch

0845 123 2307 03000 683 000

Monday to Friday, 8:30 a.m. to 5:30 p.m.

The British Institute of Human Rights (BIHR) is an independent charity working to bring human rights to life here at home.

We empower people to:

know what human rights are (and often what they are not)

use human rights in practice to achieve positive change in everyday life without going to the courts, and

to make sure those in power **respect** and progress our human rights laws and systems

At the heart of everything we do is a commitment to making sure the international promise of the Universal Declaration of Human Rights, developed after the horrors of World War II, is made real here at home.

We want to achieve a society where:

human rights are respected

human rights are at the heart of our democracy

the communities we live in value the equal dignity of each person

BIHR has been working on human rights in healthcare for over 15 years, training 1000s of people from NHS trusts, social services, and voluntary organisations to use human rights to make a difference.

BIHR would like to thank the Department of Health for their grant which supported the production of this booklet. BIHR would also like to thank all the organisations and individuals who helped to produce this booklet.

BIHR's booklets aim to empower people to have their rights respected. If this booklet has helped you to use human rights, we would love to hear your story. You can contact us by emailing info@bihr.org.uk

About this booklet

This booklet was funded by the Department of Health. We would like to thank the Department of Health for their grant which supported the production of this booklet. The BIHR staff team would also like to thank all those organisations and individuals who helped to produce this booklet, particularly **Autism Initiatives, ncompass, and NHS Merseycare** for their ideas, advice and guidance.

This booklet aims to provide people living with learning disabilities and / or autism with reliable information that helps them use human rights to have more say over decisions made in health and care environments.

This project aims to make sure people living with learning disabilities and / or autism have more **control over decisions** about their treatment,

and to make sure they are **treated with dignity and respect.**

The project is funded by the Department of Health, so the information in this booklet focuses on English law and bodies.

This booklet is to help you understand your rights.
It is not legal advice.

Your notes

Space for your notes about what you've read

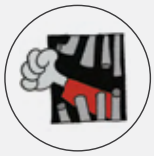
Your notes

The rights protected by our Human Rights Act:

Right to life
(Article 2)

Right not to be tortured or treated in an inhuman or degrading way
(Article 3)

Right to be free from slavery or forced labour
(Article 4)



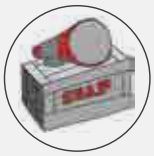
Right to liberty
(Article 5)

Right to a fair trial
(Article 6)

Right not to be punished for something which wasn't against the law when you did it
(Article 7)

Right to respect for private and family life, home and correspondence
(Article 8)

Right to freedom of thought, conscience and religion
(Article 9)



Right to freedom of expression
(Article 10)

Right to freedom of assembly and association
(Article 11)

Right to marry and found a family
(Article 12)

Right not be discriminated against in relation to any of the human rights listed here
(Article 14)

Right to peaceful enjoyment of possessions
(Article 1, Protocol 1)

Right to education
(Article 2, Protocol 1)

Right to free elections
(Article 3, Protocol 1)

Abolition of the death penalty
(Article 1, Protocol 13)

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