



The independent review of
**Learning Disability
and Autism**
in the Mental Health Act



Final report from the review

Easy read version

January 2020



This report was written by Andrew Rome, Catherine Evans and Simon Webster.

We made all of the decisions in this review.

A report called 'How we did this review' will tell you about the people who took part in the review.

The review had **advisors**.

Advisors helped us to decide how to do the review.

The advisors did not make decisions.

Some advisors were autistic, or had learning disability, or were unpaid carers.

Some advisors were professionals.

We thank everyone who helped us to run the review.

Near the end of the review, we asked some **experts in the law** to help us.

The experts did help Andrew, Catherine and Simon but the legal experts are not responsible for this report.

We thank the experts in the law. The experts were

Cathy Asante

David Cobb

Ronald Franks

Andrew Lennon

Alex Ruck Keene

Leo Starrs-Cunningham

Professor Jill Stavert



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A message from Andrew Rome



I am Andrew Rome.

I was the **Chair** of the review.

The **Chair** was the person in charge of the review.



The review was how we checked if the law was working for autistic people and people with learning disability.

The review was about a law called the Mental Health Act.

The Mental Health Act is about care and treatment for people who have a mental disorder.



Mental disorder can mean mental illness.

An example of mental illness is depression.

Mental disorder can also mean learning disability or autism.

A message from Andrew Rome

The review was independent. This meant that no group of people could say how the review should happen or what it should say.



We spoke to people with learning disability and autistic people.

We spoke to professionals and carers too.



Thank you to everyone who has told us what they think in this review.

The review was in three parts. Each part was called a 'stage'.



In stage 1, we found out what people's experiences were of the Mental Health Act.

We found out how the Mental Health Act affects people's **human rights**.



Rights

Human rights are the basic rights and freedoms that belong to every person in the world.

A message from Andrew Rome



In stage 2, we asked people for ideas of how to make the law better.

This is needed so that the law is better at supporting people's human rights.



Then we thought about everything that people had told us.



In stage 3, we told everyone about ideas for how the law could be in future.

People told us what they thought about those ideas.



Then we wrote the final report for the review. That is what you are reading about now.

This report says how the law should change for people's human rights.

A message from Andrew Rome



The report is for the **Scottish Government**.

The report tells the Scottish Government how the law may need to change.

The **Scottish Government** is the politicians who are chosen to make decisions for Scotland, and the people who work for those politicians.



If the law changes, it will be the **Scottish Parliament** that changes the law.

The **Scottish Parliament** are politicians that the people of Scotland choose.

A handwritten signature in black ink, appearing to read 'A Rome'.

Andrew Rome, Independent Chair of the Review



1

**What this
report says,
in a few words**

1 What this report says, in a few words



This report is about how the law should change for autistic people, and people with learning disability.

2 Autism, learning disability and mental health



There should be a new law for autistic people, and people with learning disability.

This is to make sure that their human rights are protected.



There should be other changes in law. Those changes would also be about human rights.

Those changes are for law that affects other people too.

1 What this report says, in a few words

3 Support for making your own decisions



People should be able to say what they want for support, care or treatment.

People can put this on paper if they want to.



People should have all of the support that they want and need to say what they want from professionals.

Professionals should support people to do what those people want to do.

4 Support, care and treatment



Support, care and treatment should be accessible for autistic people and people with learning disability.

Support, care and treatment should meet people's needs.



Women and children should have support, care and treatment that protects their human rights.

1 What this report says, in a few words

5 Where support, care and treatment happens



Autistic people and people with learning disability have a right to live independently, and to be included in the community.



There should be places where people can go when they have a crisis.

There should be professionals who can help with a crisis.

If people go to hospital, it should only be for a short time.

6 How professionals make decisions



When professionals make decisions, they should always respect what you want. They should protect and promote your human rights.



Professionals should only be able to limit people's human rights when this will help the person's human rights, overall.

Professionals should have some new roles in making decisions.

1 What this report says, in a few words

7 How decisions are checked



Groups that are led by autistic people or people with learning disability should be able to change what happens in Scotland in future.



There should be a new commission. This commission would protect the rights of autistic people and people with learning disability.



The Mental Health Tribunal should make all its decisions about human rights.

It should have power to make services give people what they want and need.



The Tribunal should be accessible to everyone.

1 What this report says, in a few words

8 People who do crime



Everyone who needs support to understand their trial should have support.



Some people who do crime do not understand what a crime is. They should not be held responsible for a crime.



Punishments may have to be adapted (changed). For example, a prison might have to make changes for a person.



People should be able to get care or treatment wherever they are. This might be in prison, in the community, or somewhere else.

9 Support, care and treatment for people who do crime



Some people who do crime go to secure units. People should get out of these places by the same time that people would get out of prison.



2

Autism, learning disability and the law

2 Autism, learning disability and the law



This report

Most of the things we say in this report are about autistic people and people with learning disability.

If we just mean autistic people we will say so.

If we just mean people with learning disability we will say so.

The law

Autism and learning disability should not be called mental disorders in law.

The law should change so it does not call learning disability and autism mental disorders any more.

There should be a date set for when this happens.

Some things need to happen before the law is changed.



2 Autism, learning disability and the law



A new law for people with learning disability and autistic people.

There should be a new law for people with learning disability and autistic people.

This would be just about making things better for people. It would not be about making people do things that they don't want to do.

There should be changes to services to make them better.

There should also be new law to protect everyone who is at risk of serious harm.

The new law should be for everyone, not just people with 'mental disorder or disability.

2 Autism, learning disability and the law



Disability and human rights

The law should use the same words that are in the Convention on the Rights of Persons with Disabilities. A **convention** is an agreement that countries make.

The law should say that when people make decisions about someone else, the decisions have to be about human rights.

If someone wants to make a decision for someone else they have to show that this will be much better for the person's human rights.

The law should talk about human rights. It should use the same words that are used in conventions on human rights.

Legal capacity

'Legal capacity' is about having rights. It is also about having duties, which means things that you have to do.

People have to get all the support they need to help them use their rights.





3

Support for making your own decisions

3 Support for making your own decisions

Statement of rights, will and preferences



There should be something called a statement of rights, will and preferences.

This is something a person can say or write that tells others what matters to them. The person can use pictures or anything else.

The statement tells other people what the person wants to happen. It would be other people's job to make sure that this happens.



If there is a reason why it cannot happen this has to be explained.

The reason why it can't happen could be that it is not possible.

The reason why it can't happen could be that it would be a crime.

There would have to be checks to make sure that this was the right decision.

The person could challenge the decision.

3 Support for making your own decisions



Independent advocacy

We say that everyone should get advocacy unless they say no.

People who cannot ask for an advocate should be given an advocate.



Decision supporters

There is another review of the law.

That review may think about how other people like family and friends can help people to make their own decisions.



Unpaid carers

Many people have unpaid carers like family members or friends.

Unpaid carers are important.

Unpaid carers often know how to communicate with people.

They often know what people like and don't like, for people who cannot speak for themselves.

Unpaid carers also have human rights. They should be respected.

3 Support for making your own decisions



Information from professionals

Professionals are people who have special training, skills and knowledge. A professional is paid for what they do.

Professionals should give information to everyone in ways that people can understand.

Psychological therapy

This is help for how people think and feel.

People should be able to choose the help that they want.



Medicine

Some people take medicine to help their mental health.

Some people take medicine to control how they behave.

The Government should make sure that people are only getting medicine that helps them.

People should be able to choose the medicine that they want.

They should have support to come off of the medicine.





4

Support, care and treatment

4 Support, care and treatment

Access

Autistic people and people with learning disability should be able to get access to the support, care and treatment that they need.

Services and buildings should be **accessible**.



Accessible

Accessible means that there is nothing that stops people from using a service or a building.



Autistic people and people with learning disability should have the chance to lead changes in their services.

They should have the chance to lead changes in how buildings are made.



The law should make sure that the people in charge of services give people the services that they want and need.

4 Support, care and treatment

Services that people need

Here are some of the services that people need.



Diagnosis, to tell people that they are autistic or that they have learning disability.



Health checks. Many autistic people and people with learning disability have much more ill-health than other people.



People need these services. This includes people who have done crime.



There should be a service that works across all of Scotland. It should help other services to get better at working with autistic people.

4 Support, care and treatment

Women

Gender should always be thought about when people are making decisions.



Children

Children have extra rights.

Children's rights should always be thought about in decisions.



Parents should have help so that they can support their children.





5

**Where support,
care and treatment
happens**

5 Where support, care and treatment happens

Independent living



Autistic people and people with learning disability have a right to live independently, and to be included in the community.



People should be able to choose where they live.

People should be able to choose who they live with.



Support should make it possible for autistic people and people with learning disability to be in the community instead of living in hospital.

5 Where support, care and treatment happens

Safe places



There should be places where people can go when they have a crisis.

These should be places that are not hospitals.

Community rehabilitation



Rehabilitation is supporting people to get skills back that they used to have.

There should be professionals who can stop crises from happening.

They would also help people to move back to the community.

Hospital, mental health and crisis



People should only go to hospital when it will clearly help their human rights.

People should not live in hospital. It should only be for a short time.



6

How professionals make decisions

6 How professionals make decisions



Rights

Human rights assessments

When professionals make decisions, they should always think about human rights.

Their decisions should always respect what you want.



Their decisions should always protect your human rights.

Professionals should also think about other people's human rights.



Limits on human rights

Some human rights can be limited. This means that people can sometimes be stopped from doing what they want to do.

This can be done to protect other human rights that cannot be limited, like the right to life. The right to life is an absolute right.

For example, a person's liberty (freedom) might be limited at times, to protect their right to life.



6 How professionals make decisions



A person's human rights might also be limited to protect other people's human rights.



Professionals should support people to do what they want to do.

Professionals should give people the support, care or treatment that they want



Professionals should only be able to limit people's human rights when this will help the person's human rights, overall.



Professionals should make decisions in the same way for autistic people, people with learning disability, and other people.

6 How professionals make decisions

What professionals decide



Autistic people and people with learning disability should have the professionals that they want and need.

Professionals should have some new roles.



Care co-ordinators would make sure that people have the support, care and treatment that they want and need.

Care co-ordinators would be social workers, occupational therapists or nurses.



Human rights officers would check that decisions will protect and promote human rights.

Human rights officers would be social workers.

6 How professionals make decisions



Lead clinicians would be psychiatrists (doctors), nurses or clinical psychologists.

Clinical means that they work with people who have poor mental health.



The **responsible officer** would be in charge of social work, for the area where the person usually lives.

The responsible officer would make sure that orders from the Mental Health Tribunal for Scotland happen. Page 37 is about the Tribunal.

Orders are decisions that the Tribunal makes. They tell a person or organisation what to do.



7

How decisions get checked

7 How decisions get checked



Disabled Persons Organisations

This is about groups that are led by people with learning disability.

These groups should be able to change what happens in Scotland in future.

They should have the money that they need.

Groups should be listened to. People who have lived experience should be listened to.

The same things should happen for autistic people's organisations.

Commissions and inspectors

A **commission** has power to do something for the government. For example, a commission can have power to make sure that people's rights are respected.

An **inspector** visits people to make sure that their support, care or treatment is good enough.



7 How decisions get checked



There should be a new commission. This commission would protect the rights of autistic people and people with learning disability.



A commission should set standards (rules) for support, care and treatment.

These standards should be based on human rights.



Inspectors should make sure that people's human rights are respected.

They should make sure that the standards are met.



If commissions or inspectors find that people's human rights are not respected, they should be able to make services change.

They will need to have power to make services change.

7 How decisions get checked

Mental Health Tribunal

The Tribunal makes decisions.

It decides whether people's rights should be limited.



The Tribunal decides whether people should be made to stay in hospital.

It decides whether people should be made to have treatment, even if they do not want it.



In future, the Tribunal should make all its decisions about human rights.

They should check that people's human rights are being met.

The Tribunal should have power to make services give people what they want and need.



The Tribunal should be accessible to everyone.



8

**People who
do crime**

8 People who do crime



Some people do crime.

Crime is doing things that are against the law.

Some of those people are autistic people or people with learning disability.



When the police have to speak with a person, they should ask the person if they have a disability.

This would help the police to work well with autistic people and people with learning disability.

Trials



Trials are when decisions are made about whether someone did a crime.

Some people do not have trials because they might not understand the trial.



Communicate

In future, everyone who needs support to understand their trial should have support.

8 People who do crime



Responsibility

If you are responsible for a crime, this means that you have done the crime and it is your fault.

It should be possible for autistic people and people with learning disability to be held responsible for a crime.



But some people who do a crime do not understand what a crime is.

Those people should not be held responsible for a crime.



Punishment

If an autistic person or person with learning disability did a crime and they knew they were doing wrong, they should be punished.

The punishment should not have a worse effect on the person than it would have on anyone else.



The punishment might have to be adapted (changed). For example, a prison might have to make changes for the person.

8 People who do crime

Treatment



Some autistic people and people with learning disability who do crime need care or treatment.

They might need this for their mental health.



People should be able to get care or treatment wherever they are.

This might be in prison, in the community, or somewhere else.

Support to live well and not do crime



People should have the support that works for them.

The support should help them to live well and to stop doing crime.

Safety of other people



Decisions should be about everyone's human rights.

Decisions should include the human rights of people who are victims of crime.



9

**Where support,
care and treatment
happens
for people
who do crime**

9 Where support, care and treatment happens for people who do crime



Community

Autistic people and people with learning disability who do crimes should live in the community, if other people would live in the community after the same crimes.



Learning new skills

Some autistic people and people with learning disability who do crime go to hospital wards.

These places should change from places that focus on medical treatment, to places that focus on skills for living in the community.

People should get out of these places by the same time that people would get out of prison.



Prison

The prison system should change so that it works well for autistic people and people with learning disability

10 A list of words that we use in this report

These words are all in this report. Here are explanations of what we mean by these words.

Absolute rights	Human rights that should never be limited. Some other human rights can sometimes be limited.
Accessible	This means that there is nothing that stops people from using a service or a building.
Autism	A lifelong condition that affects how people think, how people communicate, how people relate to other people, and how people experience the world around them.
Autistic People's Organisation	An organisation run by and for autistic people.
Care co-ordinator	Care co-ordinators would make sure that people have the support, care and treatment that they want and need. Care co-ordinators would be social workers, occupational therapists or nurses.
Chair	The person in charge of the review.
Clinical	This is about work with people who have poor mental health.
Clinical psychologist	A professional who is an expert in psychology for mental health.

10 A list of words that we use in this report

Commission	A commission has power to do something for the government. For example, a commission can have power to make sure that people's rights are respected.
Convention	An agreement that countries make.
Crime	Doing things that are against the law.
Diagnosis	A decision from a clinician, like a doctor or a psychologist. A person may get a diagnosis that they are autistic or that they have a learning disability, for example.
Disability	What a person experiences when they have impairments, and when there are barriers in society that affect them.
Disabled Persons Organisation	An organisation run by and for people with disability.
Duties in law	Things that people, organisations or governments have to do.
Human rights	The basic rights and freedoms that belong to every person in the world.
Human rights assessment	A way of checking that people's human rights will be protected and promoted.
Human rights officer	A social worker who checks that decisions will protect and promote human rights.

10 A list of words that we use in this report

Independent Advocate	Someone who helps you to understand your rights and to say what you want. They are independent because they are not controlled by other services.
Inspector	An inspector visits people to make sure that their support, care or treatment is good enough.
Intellectual disability	Also called learning disability. A lifelong condition that affects how people understand information, learn skills and live independently.
Law	The rules that a government makes for the people who belong to a country.
Learning disability	Also called intellectual disability. A lifelong condition that affects how people understand information, learn skills and live independently.
Legal capacity	This is about having rights and duties in law. It is also about using rights, and doing the duties that you have in law.
Limits to human rights	Sometimes people can be stopped from doing what they want to do. This can be done to protect other human rights that cannot be limited, like the right to life.
Mental disorder	In the Mental Health Act, these words mean mental illness, learning disability, personality disorder, and other mental conditions.

10 A list of words that we use in this report

Mental health	The way you think, feel and behave.
Mental Health Act	<p>A law called the Mental Health (Care and Treatment) (Scotland) Act 2003.</p> <p>This is Scotland's main law about care and treatment for mental illness, personality disorder, learning disability, and other conditions that are called 'mental disorders'.</p> <p>This law says how you can be treated if you have a 'mental disorder'.</p> <p>It also says what your rights are.</p>
Mental illness	<p>A problem with mental health.</p> <p>The main mental illnesses are depression and anxiety.</p>
Mental Health Tribunal for Scotland	<p>A part of the legal (law) system in Scotland.</p> <p>It makes decisions about the Mental Health Act for people with mental disorder.</p>
Nurse	A professional who is an expert in support, care and treatment.
Occupational therapist	A professional who is an expert in support and skills for independent living.
Orders	<p>Decisions from the legal (law) system.</p> <p>Orders tell a person or organisation what to do.</p>

10 A list of words that we use in this report

Psychiatrist	A professional who is an expert in medicine for mental health.
Professional	A person who has special training, skills and knowledge. A professional is paid for what they do.
Rehabilitation	Supporting people to get skills back that they used to have.
Responsible officer	This would be the person in charge of social work, for the area where an autistic person or person with learning disability usually lives. The responsible officer would make sure that orders from the Mental Health Tribunal for Scotland happen.
Scottish Government	The politicians who are chosen to make decisions for Scotland, and the staff who help them in their work. The politicians make decisions about health, social care, justice, education, housing, human rights and other things.
Scottish Parliament	The group of politicians who represent people from all parts of Scotland. The Scottish Parliament makes most of Scotland's laws.
Social worker	A professional who is an expert in support for relationships and social problems.