



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

**Report about stage 1 of the review**

May 2019

## **A note from the Chair of the review**

In Scotland, the public and our professionals working in health and social care settings care deeply about those of us whose human rights are most at risk.

In 2001, the Millan Committee said that learning disability and autism should be covered by Scotland's Mental Health Act, but that this should be reviewed. In this review, we are considering whether this Act should continue to apply to autistic people and people with learning disability.

In stage 1, the review team spoke to people across Scotland with experience of being under the Mental Health Act. Some people told us about how this helped to provide the care that they needed at the time. We did hear of some negative experiences, particularly about being in hospital.

People's stories also told us that, even when good care is provided, the Mental Health Act sometimes fails to protect people's rights. We also heard that the Act sometimes makes it legal for public services to do things that have negative effects overall on people's human rights.

I need to say a huge thank you to all the people who took part in stage 1, especially to people with lived experience. I really appreciate your time, effort and honesty. Also, the review's advisors have helped us in trying to make sure that the review's work fully respects people's human rights. I am grateful for their expertise. Our advisors are extraordinary people with lived experience, professional experience or both.

This report is from me, along with Catherine Evans (Project Manager) and Simon Webster (Secretary). I look forward to providing our final report and recommendations in December 2019.

Andrew Rome

Chair of the review

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<b>A</b>	<b>Introduction</b>
	What this report is about

This review is about people's lives and experiences.  
It is also about human rights.

Human rights are the basic rights and freedoms that belong to every person in the world. They are not always respected.

Autistic people and people with learning disability are less likely to have their human rights respected than many other people.

When it was written, Scotland's Mental Health Act (a) was one of the best mental health laws in the world for human rights.

After that, the United Nations realised that governments were not doing enough on human rights of people with disabilities.

This is why the United Nations made the Convention on the Rights of Persons with Disabilities.

It seems that there is no mental health law in the world that meets all the human rights standards in that Convention.

The Scottish Government has to try to make all Scots (Scottish) laws fit with that Convention, and with other human rights. For example, every Scots law has to fit with the European Convention on Human Rights.

This is often very difficult as the United Nations itself does not agree on what some standards mean.

We do believe that Scots law **can be better** at promoting and protecting human rights.

This report should help Scottish Government to understand **why** the law needs to change.

Our final report should help Scottish Government to decide **how** to change the law, if it feels this is necessary.

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(a) The full name of Scotland's Mental Health Act is the Mental Health (Care and Treatment) (Scotland) Act 2003

## **How we think about human rights in this review**

You can see what rights we are thinking about in the review's human rights framework (click for [link](#)).

Human rights must be balanced at times. While it can be justified for governments and public services to restrict (limit) some human rights at times, some rights can never be limited.

Where the Mental Health Act is working well, we expect to see evidence that, overall, there is a positive effect on people's human rights.

Some breaches of human rights can affect a lot of people.

Some breaches can affect a few people, but their rights can be very badly affected.

Some autistic people and people with learning disability may be completely unable to protect their own human rights.

All of these people, and all of their rights, are important.

The law has to try to make sure that human rights are protected, promoted and fulfilled for all of these people.

Scots law also has to protect the human rights of everyone, including people who are more able to protect their own rights.

In this first stage of the review, we used human rights to help us to decide what evidence (information) to look for.

We also used human rights to help us to bring together and understand everything that people told us, and all of the reports that we read.

In the human rights framework, you can see that we are thinking about all of the rights that contribute to mental health.

We are also thinking about the human rights that can be breached when mental health law is used.

<b>A</b>	<b>Introduction</b>
	How to read this report

We hope that everyone will be able to understand what this review finds out.

There will be an easy read stage 1 report by August 2019.

Everything that we say in this report is about the experiences of autistic people **and** people with learning disability, unless we say something different.

We always say when an experience is only about autistic people, or is only about people with learning disability.

### **What this report is not**

This is not a report from an inquiry. There have been several inquiries into failures in mental health services in the UK. This is a review of the law, not a review of any services.

This report does not make any recommendations (suggestions for change). The final report will make recommendations that the Scottish Government may choose to follow.

### **What this review is about**

This report tells you what we found in stage 1 of the review.

The report is about experiences of Scotland's Mental Health Act for autistic people and people with learning disability.

The report is based on the experiences of autistic people, people with learning disability, carers and professionals.

In this review, and in this report, we are giving the same weight (importance) to what people with lived experience tell us and to what professionals tell us.

It was important for the review team to meet or speak to people with lived experience. We did this across Scotland, in hospitals and in the community.

We are very grateful to people for sharing their experiences and thoughts with us. We have not included specific examples of the experiences people told us about because we need to protect people's anonymity (privacy). We have summarised the key points people made. But people's full experiences have been considered by review team members.

It was also important for us to read reports that had been written before this review, by people with lived experience and by professionals.

### **What is unusual about this report**

This report gives insight into the extent to which Scotland's Mental Health Act promotes and protects the human rights of autistic people and people with learning disability.

We let people tell us about their experiences in lots of different ways. We always allowed people to choose what to tell us about, from their experience of the Mental Health Act.

The report looks unusual because of this.

### **How stage 1 evidence was used**

In stage 1 we found out people's experiences of the Mental Health Act and how the Act affects people's human rights.

We used what we found in stage 1 to shape what we would talk about in stage 2. Stage 2 is about suggestions for how the law could promote and protect human rights better in future.

You will see the results of stage 2 in the information that we give out at the end of August 2019. That information will be for everyone to give views on, in stage 3, before the final report.

<b>A</b>	<b>Introduction</b>
	A description of this review and stage 1

**A review is when people look at the law and see if it needs to change.**

The review is about a law called the Mental Health (Care and Treatment) (Scotland) Act 2003. We will call this the **Mental Health Act**.

This review is looking at whether this law needs to change for people with learning disability and autism. We are finding out how well the law is supporting people's human rights.

This review is **independent**. This means that no group of people can say how the review should happen or what it should say. The review will finish in December 2019.

On our website there is more information about the review, including videos and easy read information: [www.irmha.scot](http://www.irmha.scot)

Scottish Government set the **remit** for the review. The remit is the list of things that we need to talk about and report on:

“The review will need to gather evidence from a wide range of sources and engage widely with those who have an interest, whether that interest is personal or professional and reflect this evidence in its final analysis and recommendations. The objectives of the evidence-gathering and analysis will focus on:

The operation of the 2003 Act – are people with autism and learning disability well served?

Increasing the role of psychologists in relation to the 2003 Act (we are looking at ‘*the role of psychology*’ in the Act)

The definition of mental disorder under the 2003 Act in relation to learning disabilities and autism

The criminal justice system and the interaction with the Act

The use of psychotropic medication (current prescribing practices)”

It was very important to **include people with lived experience in stage 1**. We had to do this to really understand things. Also, the United Nations tells us that we have to do this.

In stage 1 we wanted to **find out how the Mental Health Act affects people's human rights** including all of our remit.

We wanted to find this out from people. This includes people with learning disability, autistic people, carers, and professionals. We call this "**new evidence**".

We also wanted to find this out from what people had already written. We call these sources "**reports**". These include articles in journals, news reports and other written reports. The reports are about mental health and rights in general, not just the Act.

Before stage 1 began, we chose advisors for the review. We had the same number of advisors with lived experience and professional advisors. The advisors helped us make sure that stage 1 was accessible to people and that the review could get the evidence that it needed. The advisors do not decide what the review should do. Only the review team makes decisions.

To include people with lived experience in stage 1, we did this:

We checked out our ideas for stage 1 with our advisors before we made our plans.

We created Talking Mats (symbols sets within a communication system) that people could use to tell us about their experiences of the Mental Health Act. The Talking Mat was based on our human rights framework. So, what people told us helped us to understand how the Act affected their human rights.

We had an online survey for people who preferred not to meet with us or to talk on the phone. We created an easier survey. This used plain language and the symbols from Talking Mats. Our advisors gave us advice about the surveys.

We asked all relevant independent advocacy services across Scotland to support people to take part in stage 1.

<b>B</b>	<b>Stage 1 evidence</b>
	What we did to collect evidence

‘Evidence’ is all of the information that tells us something about how well the law promotes and protects human rights.

### **New evidence**

For people with learning disability and autistic people, we offered to come to talk with people face to face.

We used the Talking Mat, or the easier survey, or we talked.

For people who could not take part because they could not speak to us, we offered to meet with carers or family members face to face.

For other carers and for professionals, we asked people to use our surveys online or on paper.

We wrote to all hospital wards for people with learning disability, and for people with mental health problems.

We phoned wards to ask if we could visit and speak to people.

We wrote to all health and social care partnerships and chief social work officers. We also contacted some health and social care community teams directly.

We wrote to professional organisations and Disabled Persons Organisations. We also wrote to carer organisations.

We wrote to all carers’ centres.

We wrote to all mental health service user groups that we could find out about.

We asked people to tell us about their experiences of the Mental Health Act.

We asked people to tell us about how human rights are affected by the Mental Health Act.

We also asked people about their experiences of the specific parts of the review's remit:

- Medicine for mental health (psychotropic medication)

- Psychology

- The criminal justice system

- Autism and learning disability as 'mental disorders'

## **Reports**

The review's Secretary collected information that might be relevant to the review, from lots of different sources.

The review team talked about what other information we need.

We asked our advisors to suggest other information we might need.

The Secretary looked for the information that was suggested and included the reports that met the *criteria*.

The criteria were

- The report has to be about Scotland

- The report has to be about learning disability or autism AND about mental health

- Or the report had to be about mental health law

- The report had to be written in English

Some papers were about care and treatment, and some were about criminal justice.

We included reports that were written in the last 10 years.

<b>B</b>	<b>Stage 1 evidence</b>
	The evidence we collected

### **New evidence**

**103** individuals and **4** organisations with lived experience took part.

**76** professionals and **17** professional organisations took part.

We carried out:

**63** visits or phone calls with people with lived experience or carers of people who could not take part themselves.

**51** people said they were male and **12** said they were female

**35** people were forensic patients. This means they were under the mental health act because they had committed an offence.

**36** people had learning disability only

**8** people had autism only

**19** people had learning disability and autism

**29** people had a mental illness at the time the Act was used

We received:

**76** surveys from professionals

**34** surveys from people with learning disability, autistic people or carers of people who could not take part themselves

**6** other surveys from carers

**17** surveys from Professional Organisations

**4** surveys from Disabled Persons Organisations

We had responses from all areas of Scotland.

We did not speak to many people who were under the Mental Health Act in the community. Most were in hospital, or had been in hospital, when they were under the Mental Health Act.

## **Reports on mental health and human rights**

The reports had been written by people with lived experience and by professionals. The reports were not all about the Mental Health Act. Some reports were about human rights which matter for mental health and which may not be emphasised in the current Mental Health Act. All reports were about Scotland.

The reports were from:

Organisations that support the rights of autistic people or people with learning disability

International organisations that decide what human rights are

A person with lived experience of mental illness

Scottish and UK organisations that monitor human rights

Psychiatrists and lawyers

Experts in mental health law, human rights, or criminal justice

Experts in health needs of autistic people, and people with learning disability

Healthcare organisations that sets standards for education, and for support, care and treatment

Scottish Government

National newspapers

The UK Supreme Court and a Scottish Tribunal

<b>B</b>	<b>Stage 1 evidence</b>
	What we did with the evidence

We used the evidence to help us to think about what we need in mental health law for people with learning disability and autistic people.

### **New evidence**

We made notes of our conversations with people. We put these notes, all the survey responses and all the notes from Talking Mats into one database.

We labelled all of the information that told us something about human rights or about a part of the review's remit.

We looked at all the suggestions that people had made and the key issues that people told us about through Talking Mats or the easier survey.

### **Reports**

We looked at all the reports that met the criteria.

The review team chose enough reports to make sure that we knew what most of the main issues are.

Some reports told us about issues we already knew about from other reports. We did not include these reports as “main papers”. We listed those reports so that we could use them later in the review.

Some of the reports gave us a good understanding of what is working well and what is not working well in mental health, learning disability and criminal justice services in Scotland.

Some other reports helped us to understand how the law promotes and protects human rights.

This helped us to decide what outcomes need to be achieved.

## **Stage 1 evidence and the rest of the review**

We used what people told us and the reports that we read to create 'outcomes' for mental health law.

All of the specific parts of our remit are reflected in the outcomes.

The main outcomes are:

People are safe in a crisis

All decisions promote and protect the person's human rights

Medicine has a positive effect for the person

Care and treatment have positive effects for the person

Criminal justice is fair and helpful for the person

The law promotes and protects all of the person's human rights

You can see all of the outcomes in the 'list of outcomes' ([link](#)).

We mapped these outcomes to the human rights that we are using in the review, so that we could refer to this as a check.

The list of outcomes helped us to think about what we need in mental health law for people with learning disability and autistic people.

We have used these outcomes to guide stage 2 of the review.

In stage 2 we asked people what they think needs to change, so that we can achieve the outcomes.

We asked what needs to change so that we can promote and protect human rights better.

<b>C</b>	<b>What we found</b>
	What the evidence told us about human rights

To write this report we looked at all the information people gave us in stage 1.

In the next pages, you will see the main things we learned from the evidence we collected in stage 1.

We put information from different people together so that we could get a whole picture of people's experiences.

When we say "some people" we mean more than one person or organisation. "Some people" could mean as few as two people.

We cannot say that the things that we found are happening everywhere.

We can only say that we were told that these things happen somewhere and to some people.

When we say "most people" we mean more than half of the people we spoke to or the people who filled in a survey form.

For our review, even if one person told us something, this can be important. We have not used numbers to say how many people said each thing. This is because sometimes numbers are small and we do not want to identify anyone.

To find a report, look for a number in brackets - for example (2) – and then find that number in the 'references for main reports'. Those references begin on page 62.

We use '**human rights themes**' to help us to understand how well rights are promoted and protected.

You can see the human rights and themes in our human rights framework (click for [link](#)).

We took out the information about each human rights theme and we decided what the main findings were for each theme.

There are nine human rights themes:

1. Standard of living
2. Health
3. Freedom and safety
4. Protection from abuse
5. Independent living
6. Dignity
7. Equality and non-discrimination
8. Accessibility
9. Implementation and monitoring

Each theme is made up of one or more human rights.

For each theme, we start by giving you the main points from the new evidence that we collected.

Then, we give you the main points from the reports that we read. The references for all the reports start on page 62.

You can click on links there to take you to those reports on the internet, or to summaries of those reports.

<b>C</b>	<b>What we found</b>
	A summary of what we found

We understand that there is a mixture of experiences and opinions about the Mental Health Act.

It is clear to us that the Mental Health Act sometimes promotes and protects people's human rights. Here are some examples:

It can make it possible to give people a safe place to stay when they are in crisis.

Sometimes if people are at risk the Mental Health Act can help them. It can save people's lives.

There are things in the Act that can protect people's rights, like the right to Independent Advocacy, the Tribunal system, and the Mental Welfare Commission.

Many professionals said that the Act worked well to promote human rights when people are ill, as the Act can get treatment for them when they are ill or very distressed and have difficulty in making decisions for themselves. Many said that treatment can work and it can mean that their health, standard of living and dignity can improve, and can lead to support after leaving hospital.

It is clear to us that the Mental Health Act does not always promote and protect people's human rights. Here are some examples of what people have told us:

Being in hospital can make people's health, standard of living and independence worse. Sometimes people do not feel safe in hospital.

For autistic people, the Mental Health Act does not ensure they get any treatment. It does not ensure they get the treatment that is right for them.

Some of the treatment people with learning disability and autistic people get makes people's health worse. It can affect their dignity and freedom and safety.

For some people with learning disability and autistic people the Mental Health Act does not promote and protect their human rights well. They are made to stay in hospital for longer than other people, sometimes far away from home. They can be made to be in hospital without having mental illness and they can be kept there even if they are ready to leave. The Mental Health Act may enable this, even though this may breach (break) many human rights.

### **The Mental Health Act and international human rights law**

We know that Scotland's Mental Health Act does meet many of the human rights standards that are set by the European Convention on Human Rights (a).

We know from the United Nations' reporting that Scotland's Mental Health Act does not meet the standards of the Convention on the Rights of Persons with Disabilities (b).

This stage 1 report says a little about the strengths and weakness of the Mental Health Act as a law. This report is mainly about people's experiences of the law. Most of our information about the Mental Health Act as a law will be in the final report.

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(a) Examples of this can be found in the book 'Mental health, incapacity and the law in Scotland' by Patrick and Stavert

(b) See reference 2 in the list of reference on page 62

<b>C</b>	<b>What we found</b>
	1. Standard of living

This theme includes:

The right to respect for privacy

The right to an adequate standard of living and social protection (benefits and supports)

### **Standard of living: New evidence**

Sometimes people's standard of living had caused their health to get worse and meant they ended up in hospital.

Some people's standard of living was better in hospital than it had been before hospital.

Sometimes getting support and treatment helped people to improve their standard of living.

Some people said that being in hospital meant people had a very poor standard of living. For example they might not be able to go outside or do the things they need to do.

Many people said that they wanted to leave hospital. People said it is not a home and they just wanted to get out.

Sometimes people went back to a worse standard of living after leaving hospital.

Some said that the Mental Health Act helps because it says that people have to be supported when they are discharged from hospital.

However people said that this bit of the Act is not used very well.

## **Activities and getting out and about**

Activities and getting out were important to lots of people.

In hospital, there were activities for some people some of the time.

Some people told us about a lack of daily activities and that people were on their own or bored a lot of the time. Most people couldn't get out much. Some people couldn't get out at all.

Some people could not do activities because they were on medication. Other reasons were given such as that it was too risky, or because staff were not available. If people were considered to be at risk they might not be able to do things that would improve their standard of living like take showers. Activities such as listening to music and watching films might be not allowed.

Some of these activities might be especially important to autistic people as a way of coping with the hospital environment.

We were told that people are less likely to be able to have opportunities like going on holiday or getting work experience.

## **Environment**

Sometimes the ward environment made people's health worse. This can be a particular problem for autistic people. This could be because it is noisy and not suitable for them. Sometimes, the ward environment can be in a bad condition.

People told us that the ward environment could be very controlled and regulated. There are a lot of rules which people said can feel stifling. Some people said they felt like children.

## **Food**

People told us that the food in the hospital was not always great, and people didn't always get the food that they needed when they needed it. Some people said they didn't get food that met their dietary requirements, like vegan food for example.

## **Visitors and communicating with family**

Most people we met in hospital were getting to see visitors. Other people couldn't see visitors. Sometimes this was because of the distance from home. Carers said it could be hard to visit. Some people also said their mobile phones were taken off them, making communication difficult.

## **Privacy**

Most people said they had their own rooms in hospital. Privacy was important to people, but people did not always have privacy. Sometimes people had to be watched all the time.

Some people said they find it hard being around other people.

We were told that privacy could be especially important for autistic people, and that being watched can have a greater negative impact for autistic people.

## Standard of living: Reports

Some people with learning disability are living in hospital (1).  
People should only go to hospital for care and treatment:  
no-one should be living in hospital.

Some people are staying in hospital for much longer than other  
groups of people (1, 4).

Most learning disability hospital environments are not good  
enough (4).

Some people are living far from home. This includes some  
people living in England (1).

Of these people, people with learning disability who are also  
autistic are most affected (1).

**C What we found****2. Health**

This theme includes the right to health

**Health: New evidence****The Mental Health Act and health**

Some people said the Mental Health Act helps to give treatment to people who need it.

Some professionals said that if lots of different types of professionals can be a part of someone's care and treatment, this makes their health better. Sometimes the Act helps with this.

Some people said that being detained and not having choice and control affected their health badly.

Others said that the environment in hospital affected their health badly. Seeing and being around other people who are ill affected some people badly.

Some people said they had put on weight or lost weight in hospital.

Some people said there is not enough specialist help for autistic people and for people with learning disability.

Some people said they felt that they had to reach crisis point before they were able to get help for their mental health.

Some said that the Act is only set up to deal with medical treatment. It is not set up to deal with treatment that works for autistic people.

## **Health in the community**

Some people said that poor support in the community has a bad effect on autistic people's health.

Some autistic people said that they were not able to get any help for their mental health or their autism.

Some people said that when they were discharged from hospital there was not enough follow up support to keep them healthy.

## **Crisis**

Some people said that when they had a crisis, they did not have a helpful response. It felt scary and they did not know what was happening.

Some people said they did have a helpful response.

## **Health and autism**

A poor understanding of autism and poor care under the Mental Health Act made some autistic people's health worse.

Some autistic people said that they think staff do their best to understand autism. Some autistic people said it was important that autism is in the Act, because they think it would ensure that they get better access to care, support and treatment.

## **Health inequalities**

People told us that both autistic people and people with learning disability have poor health outcomes compared with other people. There is more about this in the "equality and non-discrimination" section.

## **Choice about health**

Most people in hospital said they do not have any choice about treatment or medicine.

Most people we met did not have an Advance Statement. This is a written statement that says what care and treatment the person wants when they are under the Mental Health Act.

## **Physical health**

Some people said that being under the Mental Health Act helps people get other help for their physical health.

Most people in hospital said they did get help with their physical health when they needed it. Some people told us they did not get help with physical health problems.

## **Psychotropic medication** (medicine for mental health)

Most people in hospital who said they are given medicine said that it was OK. Most said they were given information about their medicine.

Some people said that medicine helped them to feel better. Some said it helped them to move on from hospital.

Some said it had been hard to find the right medicine for them.

Other people said that medicine can make people's health worse or can cause mental illness.

Some told us that the side effects from medicine are bad and can be worse than any illness itself.

Some people said that autistic people can react differently to drugs and they thought that professionals often do not accept this.

Some people told us that medicine is given to people sometimes to control behaviour, not to treat illness.

People said that medicine can be given too quickly without trying other things.

People told us that once someone is given medication it can be very hard for them to stop taking it. Some people had experience of reducing medication and said that this helped the person a lot.

## **Psychology**

Most people in hospital said they had had help from staff to change how they think, feel and behave.

Some people said psychology was very helpful to them. It helped them to change the way they acted and reacted.

Other people said that talking to staff helps them with any problems they have.

Some people said they did not have access to psychology.

Some professionals said there are not enough psychologists and psychological therapies available to people.

## **Health: Reports**

### **Disability**

Disability is not understood in a way that fits with people's human rights. This has a bad effect on people's rights, including their right to health (2).

There are many barriers that prevent people with disabilities from using the same health services as other people. This includes barriers in systems, physical barriers, attitudes, and communication barriers (2).

Disabled people, particularly those with a learning disability or mental illness, are more likely to have significant health risks. They are more likely to have health inequalities and major health problems, and are likely to die younger than other people (14).

Disabled people are also less likely to have health checks, screening tests and treatment. Healthcare staff are not very aware of disability. Physical ill health is not always treated, because it can be seen as part of a mental illness or learning disability (14).

There can be little continuity in people's care, and shortages of workers (15).

People can have nowhere to go when they are in crisis or suicidal, because hospitals may not take people in (15).

### **People with learning disability**

For some people with learning disability who are in hospital for a long time, care planning is not good (4).

Some learning disability hospitals do not carry out regular health checks for people with learning disability (4).

It is possible to improve the quality of primary health care for adults with learning disabilities and serious mental illness in Scotland (8).

People with learning disabilities are at greater risk of developing mental ill-health, because they are more likely to experience poverty and abuse, and are at more risk of not having enough support. This can lead to behaviours that challenge services (9).

### **Autistic people**

There are very few specific services for adults with autism (5).

Mental health services are not accessible for autistic people (11, 12).

Autistic people may not be taken seriously about their mental health (12).

Some people are denied access to mental health services because they are autistic (12, 13).

An autistic person may not be assessed by someone who understands autism, even if their life is at risk (13).

If the person is given services, the staff in the services may not understand their needs (13).

There can be poor co-ordination between specialist and general health services for people with complex needs (13).

### **Autistic people and people with learning disability**

Setting up community support services and discharging people from hospital are not always done well (1, 13).

**Psychotropic medication** (medicine for mental health)

We do not know how many autistic people or people with learning disability are receiving psychotropic medication. We do not really know what the effects of these medications are for these groups of people (5).

National practice guidance states that people who are given any psychotropic medication should have regular reviews, to make sure that the medicine helps and is used in the right way, and to check for side effects or interactions with other medications. This does not always happen (6).

Many people with learning disability who do not have psychosis are being given anti-psychotic medications. Many people are being given these medications for 'problem behaviours'. However, these drugs should not be used for this, and they can have serious side-effects (10).

There is little support for using medication for behaviours that challenge services, when the person has no mental illness, but medication is used for this. There is some support for using interventions such as positive behavioural support (9).

It can be difficult to give a correct diagnosis of health needs for a person with learning disability (9).

Medicines may be used differently by people with learning disability who have mental illness (9).

Some autistic people believe that they respond to medication in different ways. They think that this needs more study and acknowledgement (11).

Some autistic people and their carers believe that psychotropic medication has very serious effects on them (24).

## **Psychology**

It is not clear how helpful psychology is for autistic people. One report said that research into the needs and experiences of autistic adults is limited, and that there is not enough evidence to recommend any specific psychosocial therapy (6).

Another report recommended a specific therapy, but only from therapists who have autism-specific training (7).

Some psychological therapies can help some people with learning disability who have mental illness. However, these therapies are not always accessible (9).

<b>C</b>	<b>What we found</b>
	3. Freedom and safety

**This theme includes –**

The right to equal recognition before the law. This means to have the same rights in the law to make decisions as everyone else.

The right to an effective remedy. This means that when human rights are not respected, you can get problems solved.

Access to justice. This means the right for justice systems to be accessible in every way.

The right to a fair trial

The right of appeal in criminal matters

The right to liberty and security. This means to be detained and restricted only as the law allows, and in a way that does not discriminate.

**Freedom and safety: New evidence****Making decisions**

People told us they do not have much choice under the Mental Health Act. They cannot choose where to go or what to do.

Some people were OK with others making decisions for them, but some people want to make more decisions themselves.

Most people who had advocacy said they like advocacy.

Some professionals and groups told us that they think it is harder to use advocacy if you have learning disability or if you are autistic. Advocacy workers do not get the chance to get to know some people. They might not be good at communicating with them.

Some people said that staff help people to make choices.

Some carers told us they did not feel listened to or involved in decisions about the person. Some said it was hard to get information about the person's care. This has got worse since the Mental Health Act changed and it has become more difficult for people "without capacity" to have a "named person".

### **Challenging decisions**

Some professionals and organisations said that it is harder for people with learning disability and autistic people to challenge decisions.

Some people said they find it hard to take part in Tribunals. Other people told us that there are people who listen to them.

Some people said that it takes a long time to be able to challenge a decision. Decisions can depend on the professional involved, for example whether someone is willing to take more risks.

Some people said they feel very restricted being detained under the Act. They said there are lots of rules which can be difficult to understand or difficult to follow. The rules, and decisions about restrictions, can feel unfair and arbitrary.

Some people told us that detention causes them to feel frustrated, which then causes them to lash out. If they lash out this can lead to further restrictions, which can make the problem worse.

## **Balancing freedom and safety**

Some people said the Act has to balance freedom and safety. It often takes away freedom so that someone can be safe.

People told us that principle of the “least restrictive option” helps to balance freedom with safety.

Some people said the Act can protect people who are not safe in the community. There is more about this in the “protection from abuse” section.

Some people said that treatment in the community under the Act would give people more freedom, and that this is not used as much for people with learning disability and autistic people.

## **Criminal justice**

Some people in forensic hospital said they were glad they were not in prison. Some said they would prefer to be in prison.

Some professionals and groups said that people with learning disability might not get equal access to the criminal justice system.

They said that the criminal justice system does not make adjustments for people with learning disability or autistic people.

Some people said the criminal justice system might not pick up on whether someone has learning disability or is autistic.

Some autistic people who had experience of the criminal justice system said it is important that autism is in the Mental Health Act, so that people take autism seriously and focus on it.

Some people said that autistic people and people with learning disability who commit crimes stay in hospital for longer than people who don't have learning disability or autism but commit the same crimes and go to prison.

Some people said they were not treated equally because they did not know when they would be able to leave hospital. People in prison know when they will leave prison.

One organisation said that community services think that people with learning disability and autistic people who commit crimes are more of a risk than other people. This makes it hard to discharge people from hospital.

Some people said the Mental Health Act promotes equality because it means that people who commit crimes do not have to go to prison.

### **Detention on the basis of 'mental disorder'**

Some professionals and organisations said that the definition of mental disorder is discriminatory.

This is because the Act says that people with learning disability and autistic people can be treated differently from other people. They can be detained even if they don't have mental illness.

We were told that people with learning disability are detained for longer, and that this is more restrictive than community treatment. Also, that it is harder for people to get out of hospital because their "disorder" is a lifelong condition.

## Freedom and safety: Reports

Scotland's Mental Health Act does not currently fit with the Convention on the Rights of Persons with Disabilities, as interpreted by a United Nations committee (18).

### **Detention and other restrictions**

The number of people given compulsory mental health treatment has continued to rise since the new Mental Health Act began (28).

The number of people who are detained with emergency detention powers is increasing. This type of detention gives less protection for the person's rights (28).

Some physical intervention and seclusion can happen without any procedure in place (4).

'Restraint' does not have a definition in Scotland (14).

The parts of the Mental Health Act that allow restrictions to be placed on people who are detained are not always understood and are not always used properly (14).

In Scotland, people who cannot give consent to be in hospital for care and treatment are seen as 'voluntary patients'. This does not fit with human rights (14).

### **Support to make decisions**

People have a right to support for making their own decisions. The law does not fully respect this right (2).

The Mental Health Act allows decisions to be made for another person, in that person's 'best interests'. It does not make sure that a person is offered support to express their will and preferences before decisions are made for them. The Mental Health Act does not give the highest priority to people's will and preferences (18).

The Mental Health Act allows people to write an Advance Statement when they have the 'capacity' to do this.

Professionals and the Mental Health Tribunal only have to 'have regard' to people's Advance Statements. They do not have to follow them (18).

People who are in hospitals can have good access to independent advocacy (4).

However, staff and individuals don't always know about independent advocacy, or about rights to appeal decisions that are made under the Mental Health Act. Not many people know that they can use Advance Statements to say what care and treatment they want (14).

Independent advocacy supports people to decide, express and achieve their choices. The Mental Health Act gives a right of access to advocacy, but only to people with 'mental disorder'. This does not fit with United Nations human rights (18).

The Mental Health Act does not give regulations for independent advocacy. We do not know how far independent advocacy can support people to have their will and preferences met in reality. The effect of advocacy is limited because there is not enough access to advocacy in Scotland (18).

Carers' experiences of the mental health system improved in some ways when this Mental Health Act was created. However, individual carers continued to struggle to be taken seriously by the mental health system (19).

### **Decisions about compulsory care and treatment**

It may be hard for people with learning disability to challenge decisions made under the Mental Health Act. A very high number of applications to the Tribunal are approved (20).

It may be that few people are using named persons or Advance Statements. Other than approval for Mental Health Act orders, most decisions about the care and treatment of people with learning disability in hospital are made by psychiatrists (20).

It is difficult to prove that people will be safe in the community if they are not in the community in the first place. Some Tribunals and solicitors may just agree with the psychiatrist's view (23).

Some research was done with people who had been through Mental Health Tribunals in Scotland. They had used the mental health system before this Mental Health Act began. The Act created the Mental Health Tribunal for Scotland, and those people then went through Tribunal. So, they knew what the mental health system was like before and after there were Tribunals (21).

Those people felt that there was more chance to be heard in the new Mental Health Act. But, they also felt that they did not have more influence over professional decisions, especially for decisions about psychotropic medication. People felt that the Tribunal had not changed the dominance (control) of psychiatry in the mental health system (21).

The Mental Welfare Commission for Scotland collects information on orders made under the Mental Health Act.

At one point in time in 2015, 11 per cent of people on a Compulsory Treatment Order had learning disability.

Of those people, 31 per cent were also autistic, and 68 per cent had mental illness, personality disorder or both.

People with learning disability were on compulsory orders for much longer than people without learning disability, both in hospital and in the community.

People with learning disability only (with no mental illness or personality disorder) were on these orders for the longest time.

For those people, psychotropic medication was the most common treatment.

'Physical aggression' was the most common reason for treatment (22).

## **Criminal justice**

There is a low level of awareness in the courts and other parts of the criminal justice system about the human rights of persons with disabilities (2).

There is not enough support for people with learning disability for access to justice (2).

Rehabilitation in the community does not always promote and protect all of the person's human rights. Professionals may not clearly explain their roles, their authority and the limits to their authority (3).

An inspection of a secure hospital reported that the hospital was of good quality. An issue was reported about capacity, not about the quality of the service. There was a problem for female patients who need a high security hospital (16).

People with learning disability often don't get a trial. Instead they may have an "examination of fact" that they do not take part in. Their care may then be handed over to medical professionals and taken out of the criminal justice system (23).

When people with learning disability commit an offence, their freedom may be more restricted than for other people who commit an offence (23).

## **Detention and treatment based on 'mental disorder'**

Disability is not understood in a way that fits with people's human rights (2).

People can be made to be in hospital, and can be made to have care and treatment, partly on the basis that they are autistic or have learning disability. This fits with the European Convention on Human Rights (17) but may not fit with United Nations human rights (2).

The Mental Health Act may be designed for people who can be treated and make a recovery rather than for people who have a lifelong condition that they would not recover from (23).

<b>C</b>	<b>What we found</b>
	4. Protection from abuse

**This theme includes:**

The right to life

The right to freedom from torture or cruel, inhuman or degrading treatment or punishment

The right to freedom from exploitation, violence and abuse

**Protection from abuse: New evidence****Autistic people**

We were told that in hospital, some autistic people had personal things taken away from them that they really needed, or they were stopped from doing the things that they needed to do to manage their autism.

Some people told us that they had a diagnosis of autism, but professionals treated them as if they did not have autism.

We were told that some autistic people experienced trauma as a result of these things.

We also heard that an autistic person may be misdiagnosed as having mental illness or personality disorder, and then be made to take powerful medication for a condition that they do not have.

**Safety**

Most people we met said they felt safe in hospital. Some said they felt safer in hospital than they did in the community.

Some people said they did not feel safe, and some said they felt scared in hospital.

Most people said they like the staff. Some staff help people to feel safe. Some people said they can talk to staff if anything is bothering them. They said that staff are very kind and helpful.

Some people in hospital told us that they had experienced threats or attacks from other patients. Some people said they didn't like the other patients and that they had been bullied.

Some said they had seen people being restrained which made them feel scared.

Some people told us that restraint can be especially harmful for some autistic people because of sensory issues.

Some people told us they had been treated with restraint or seclusion. These are restrictive practices. These might be used to control a person's behaviour. People told us that these restrictive practices feel like punishment.

Some people told us about injuries that had been caused as a result of being restrained.

Some people said they did not like some staff. Some told us they know people who had experienced verbal and emotional abuse from staff.

Some people felt that staff used treatment, rules and restrictions as a threat to make them behave in a certain way.

A very small number of people told us of situations in hospital in the past where people had been harmed by staff. These situations had been reported and fully investigated, with action taken to protect the person.

Having someone to talk to in private was very important to help people feel safe. Most people said they had somewhere private to go but not everyone had someone to talk to in private.

## **Treatment**

Someone suggested that the treatment people receive can feel like abuse because people have no choice. For example, if

medicine is given to calm people down then this can feel like abuse because of the side effects they have.

Some people felt that medicines can be used as a punishment or a threat.

We heard that sometimes the treatment that people got under the Act stopped them from becoming more ill and becoming more at risk.

Sometimes the treatment that people got saved their lives because it stopped them killing themselves.

Sometimes the Mental Health Act helped people to get support from a range of different professionals.

### **Protection**

We heard that sometimes the Mental Health Act was used to take people away from places where they were at risk of abuse or were being abused.

The Mental Health Act means that people can be taken to a hospital as a place of safety. Some people said there are usually no other places of safety to go to other than hospital.

We heard that the Adult Support and Protection Act is there to protect people from abuse, but sometimes the Mental Health Act is used instead because it has more power.

### **Dealing with concerns**

We heard that having access to independent advocacy is important to deal with any issues of concern. Some people said that advocacy was good for them. Some people said that advocacy is harder to get and to use if you have learning disability.

Some people told us they didn't tell anyone about things that happened, because they were scared that they would be punished for doing this. For example they were worried that activities might be taken away or they might not be able to see visitors. Some organisations told us this as well.

Some carers told us that they didn't feel listened to when they raised concerns. Some said that they had raised concerns and that they had been restricted because of this. Some said they didn't want to raise concerns because they were worried it might have a bad impact on the person.

## **Protection from abuse: Reports**

### **The right to life**

Some professionals have a very caring approach when working with highly distressed people who are at risk of self-harm or suicide (25).

However, services may not be able to respond to some people who are in severe distress and whose life is at risk (25).

### **The right to freedom from torture or cruel, inhuman or degrading punishment**

Seclusion, physical restraint and chemical restraint (through medication) are concerning for people's human rights. These things may all be happening in the criminal justice system, health services, care services and schools (2).

An incident was reported about a care home in Scotland, where an autistic person with learning disability was refused food and drink, over a period of time. The person's mental health suffered as a result of this (26).

### **The right to freedom from exploitation, violence and abuse**

We asked the Crown Office and Procurator Fiscal Service to tell us how many prosecutions there had been under the 'duty to inquire' on local authorities in the Mental Health Act (section 33). This section of the Act is for protection of people who may have been abused or neglected. This section had been used in prosecutions, but there was no information available on whether it had been used to protect autistic people or people with learning disability.

<b>C</b>	<b>What we found</b>
	5. Independent living

**This theme includes:**

The right to live independently and be included in the community

The right to habilitation and rehabilitation. This means to learn, recover or improve skills for daily living.

**Independent living: New evidence****Skills and activities**

Most people said that they are not independent in hospital.

They do not have any choice. It is hard to live independently.

Sometimes being in hospital means people lose the support they used to have in the community. They can lose their tenancy (home) and benefits.

Some people couldn't do the activities they used to do before hospital. Some had lost skills and interests they used to have.

Some people in hospital did say that they go out in the community. Some people said this is difficult to organise.

Some are told they cannot do things because it is too risky.

Some people told us that they want to do more things independently. Some feel they are not able to do things independently.

**Community orders**

We heard that community orders can help people to keep independence.

People said there are not enough community resources for people to help them to live independently.

## **Community support**

People said they think that people with learning disability and autistic people generally have less opportunity to live independently than other people.

We heard that there are not enough different types of housing and support.

People said that community places for some people can cost a lot of money.

Some people said that the Act does help, because of the principle of reciprocity (giving back to people when they have their rights limited) and because there is a duty for local councils to provide support to people.

Some people said that specialist support and support from different types of professionals can help. The Act sometimes helps to make this happen.

## **Independent living: Reports**

Scots law does not include living independently and being included in the community as a human right, with individuals' control and choice at the centre of that right (2).

Not enough resources for supporting independent living have been transferred to the Scottish Government and councils. Resources have not been protected for independent living (2).

Many persons with disabilities are still living in hospitals and other institutions, and are not given their right to live independently and be included within the community (2).

The Mental Health Act requires councils to provide care and support services for autistic people and people with learning disability. Those services should support independent living, rehabilitation and work and employment. Some councils may not be carrying out these duties (27).

<b>C</b>	<b>What we found</b>
	6. Dignity

This theme includes the right to have dignity respected always

In our view, a person must experience being valued to have their dignity respected. When other people do all they can to respect a person's rights, will and preferences, this helps to respect the person's dignity.

### **Dignity: New evidence**

#### **Choice and control**

Some people said they weren't listened to.

Some people said they didn't have any choices, or that they didn't have many choices.

Some people said they could not take part in meetings about themselves.

It can be difficult for people to use advocacy or Advance Statements which would help ensure their dignity is respected.

#### **Treatment and dignity**

Some professionals said that giving people treatment for mental illness helped them to be able to improve the person's dignity. Before treatment the person might have been doing things that harmed their dignity.

Some people told us about treatment they had been given that did not respect their dignity. For example, being held down and sedated.

## **Hospital and dignity**

Some people told us about rules in hospital that they felt took away their dignity.

Some professionals said that they think staff try hard to ensure people have dignity. Some people said it is hard to keep dignity in hospital because lots of people have to live together and staff might have to observe people all the time.

Some people told us about times when they were not allowed to do things that were important to them. This affected their dignity.

Some carers felt that people were not kept clean or looked after properly in hospital.

If the environment is difficult for people, this can affect their dignity because it can trigger emotions and behaviour which can lead to more interventions.

## **Monitoring**

Some people said that the visits from the Mental Welfare Commission help to ensure dignity for people.

## **Dignity: Reports**

Dignity is extremely important for human rights, but the reports did not use the word 'dignity'.

Elsewhere in this report, you can read about reports of situations where people were not always treated with dignity (1, 3, 4, 5, 11, 12, 13, 15, 21, 23, 26).

For example, some people were kept in hospital when they were well; some people were not taken seriously or were rejected from services; and some people had their rights breached in various other ways.

Respect for people's dignity was clear in one report, in the work of one professional group (25).

<b>C</b>	<b>What we found</b>
	7. Equality and non-discrimination

This theme includes the right to equality and non-discrimination for all people, and for women and children in particular.

## **Equality and non-discrimination: New evidence**

### **Issues in society**

People told us there are issues of inequality for both autistic people and people with learning disability in society.

For example, both groups of people have lower life expectancy than other people. We heard that one reason for lower life expectancy for autistic people is because they have a higher risk of suicide. The Mental Health Act does not address this inequality.

### **Definition of mental disorder**

Some people said that the definition of mental disorder discriminates against people with learning disability and autistic people. There is more about this in the “freedom and safety” section.

People told us that saying that someone is “disordered” because of a disability or condition creates a stigma.

### **The Mental Health Act and equality**

Some people said that the Mental Health Act does promote equality, because it makes sure people get access to treatment even if they cannot ask for it.

Some people also said the Mental Health Act promotes equality because it means that people who commit crimes but do not have criminal intent do not have to go to prison.

Some people said the Act does promote equality because of the Act's principles, and because of independent advocacy.

Some people said that the Mental Health Act does not promote equality because people with learning disability stay in hospital for longer than other people.

Some people said that people might not get equal access to the criminal justice system. There is more evidence about this in the "freedom and safety" section.

### **Experience in hospital**

Some people we met with told us that they are always treated the same as other people in hospital. Some people said they were sometimes treated the same.

Some people said that staff make sure that everyone is treated equally. Most people said they were accepted for who they are.

A few people told us about feeling that they were treated less than other people by staff because of their learning disability.

### **Adult protection**

An organisation said that if the Mental Health Act is used to protect someone from risk from someone else, this is discrimination because it is targeting the victim not the person causing the risk. There is more about this in the "protection from abuse" section.

## **Women**

Some people said that autism is not diagnosed properly in women. This means they might not get the support they need.

One organisation told us that women who have had trauma in their past can be put on wards with male patients that have male staff.

Sometimes women who have had trauma in their past have to be supervised by men under the Mental Health Act.

One person said that women are more likely to be seen as vulnerable or at risk and men are more likely to be seen as a risk to others.

Some people said there are not enough services for women. For example there are not enough forensic wards for women. This can mean women are put in hospitals far from home.

## **Children**

Some people told us about the sections of the Act that take account of children and young people. The Act says that services must be provided for children.

Some people said there are not enough services for children and young people in Scotland.

For example there is no specialist children's ward for children with learning disability and mental health problems in Scotland. This means people have to go to England if they need this care. Or they might have to go to an adult ward.

If children go to an adult ward there might not be any access to child friendly activities.

One person told us about examples where children were detained under the Mental Health Act because they were waiting for a placement.

One person said that children's services are complicated and confusing. This is especially hard for autistic people to deal with.

Some people said that the age limits for services cause discrimination.

Some people said that staff do promote equality for children. They said the Tribunal is child-centred and respectful.

## **Equality and non-discrimination: Reports**

### **All people**

It is easy for men and women with learning disability to be treated as though they are not really equal adult citizens. There is prejudice in society and in the general public (23).

Welfare reform has led to more discrimination against disabled people (15).

Scotland's Mental Health Act limits the legal capacity of people with disabilities on the basis of disability (impairments), in a way that does not happen to other people (2).

The Mental Health Act allows other people to make decisions for people who are under this law, in a way that does not happen to other people (2).

Actions under the Mental Health Act depend on a diagnosis of mental disorder. This may be discriminatory (27).

People have to have a mental disorder to have a right of access to independent advocacy. This could also be seen as discriminatory (18).

People with a learning disability or mental health condition are more likely to experience health inequalities and major health problems and are likely to die younger than other people. They are also less likely to receive health checks, screening tests and treatment (14).

Not enough work has been done in learning disability hospitals to address health inequalities (4).

A Scottish health board made a difference in addressing health inequalities for people with learning disability who are living in the community (8).

## **Women and children**

The United Nations found that there is not enough prevention of exploitation, violence and abuse for women and children with disabilities in the UK (2).

Not enough resources are given to organisations that represent people with disabilities, including women and children with disabilities. These organisations are not involved enough in planning and implementing laws and policies that affect the lives of people with disabilities (2).

Access to justice is not good enough for people with disabilities, particularly for women and children (2).

## **Women**

There is little research evidence about therapies for women with learning disabilities who have forensic and offending care needs (9).

There is a lack of available resource for female patients whose needs can only be met in a high security hospital (16).

## Children

Strategies to prevent the use of restraint with children and young persons with disabilities are not good enough (2).

No information is collected on the numbers of autistic children and young people who are given psychotropic medication (5).

No high-quality research has shown that any psychotropic medication helps autistic children and young people with their core difficulties or with their outcomes (6).

No psychotropic medications are licensed for use with autistic children and young people (6).

There is little research that directly compares psychotropic medication with other approaches (6).

Cognitive behaviour therapy may help some autistic children and young people with anxiety (6), but only when this is given in the right way by professionals who understand autism (7).

Some children and young people with learning disability, autism or both need specialist inpatient mental health care that is not available in Scotland. Instead, most have been sent to services that were not designed for them. Some have not been admitted to hospital. Some have been sent to units in England (29).

Many children and young people were distressed and under-treated at home or in unsuitable units. Sometimes, high levels of sedative medication and restraint were used (29).

Families were highly stressed. They had to manage destructive behaviours and severe self-injury in their children. Children and young people who were sent to specialist units in England had better outcomes. However, children and young people were separated from their families and from local services (29).

<b>C</b>	<b>What we found</b>
	8. Accessibility

This theme includes the right to have services, supports, environments and information that are accessible for the person.

## **Accessibility: New evidence**

### **Autistic people**

People said that a lack of understanding of autism means that autistic people cannot access any support at all for their mental health or for their autism.

Sometimes care is given which is harmful for people, because people don't understand autism.

Many autistic people told us that the environment they were in was not helpful for them.

People said there is no autism specialist service for Scotland.

### **Learning disability**

Some people said that learning disability specialist services are better at making adjustments and providing equal services.

Some people said that there are less specialist services available now and less specially trained staff. This means people have to go to general services where people do not have skills around learning disability.

When people go to places where there are no specially trained staff, people told us that the care they get is not as good for them.

Some people told us they had to go to England to get specialist treatment.

## **Rural areas**

Some people who live in rural areas had to travel long distances to get a service they need.

## **Access to decision making and challenges**

Some people said that people with learning disability and autistic people find it harder to challenge decisions.

Some people said that the information about the Mental Health Act was not accessible. Some people said that people do not get information about their rights.

Some people said that Tribunal papers were too hard to understand. This made it hard for them to understand what was happening to them and how to take part in decisions.

Some people said they do feel listened to. Others said that going to Tribunals is pointless because nothing changes.

## **Access to health care**

Some people said that some people with learning disability might not get the same checks for their physical health as other people.

Some people said that people with learning disability might get less information about their care and treatment.

Some people said they did get support from staff to understand information about their health and care. Some people said they have accessible care plans.

Some people said that the Mental Health Act helps with access to services. If you are under the Mental Health Act some services have to be given to you that are not given to other people.

Some people said that if you are a forensic patient then you will get better access to psychology and other services than other patients.

## **Accessibility: Reports**

### **Autistic people and people with learning disability**

Access to healthcare services is not good enough (2).

In general, information about healthcare is not accessible enough (14).

Access to justice is not good enough (2).

Access to independent advocacy is not good enough (14, 18, 21).

Psychological therapies may be inaccessible for autistic people and people with learning disability. Some therapies can be made accessible, but only by professionals who understand autism and learning disability (7, 9).

Autistic people and people with learning disabilities are more likely to experience delays in getting access to appropriate services in the community. This can be because there is no funding, accommodation or appropriate care provider. People then stay in hospital for longer than other patients under the Mental Health Act (27).

## **Autistic people**

Autistic people need access to autism specialists, and in general they do not have this (11, 12).

There are basic problems with access to GPs and mental health services for autistic people (12).

## **People with learning disability**

People with learning disability do not have full access to the same health services that are available to other people. Also, they do not always have access to specialist health services. These barriers contribute to their high level of health needs. The barriers also lead to avoidable and preventable deaths (9).

Mental illness in people with learning disabilities may not be detected because of poor access to services. Also, poor access to social support and communication may increase the risk of developing post-traumatic stress disorder (9).

Access to mental health services including psychology is not good enough for people with learning disability (30).

Some learning disability hospitals are good at giving accessible information. Others are not good at this (4).

People in learning disability hospitals can have no access to support for their daily living skills (4).

Rehabilitation in the community for offenders with learning disability may not be giving access to the social benefits of being in the community, such as acceptance by peers in the community, and good role models in the community (3).

**C What we found****9. Implementation and monitoring**

This theme includes the right to have your government monitor whether rights are being met.

It also includes the right of disabled people to be involved in this monitoring, and in putting human rights into practice through laws and policies.

**Implementation and monitoring: New evidence****Keeping records**

Information is not collected or made available in ways that would allow the government to fully meet its duty to monitor how people's rights are met.

People told us that no-one knows how many deaths happen in hospitals.

People told us that no-one knows how many people are assaulted in hospital.

People told us that no-one knows how many autistic people are subject to the Mental Health Act.

People told us that no one monitors how restraint and seclusion are used in Scotland.

Someone also said that when people have to go to England for hospital treatment, it is harder to monitor what happens to them.

## **Guidelines and standards**

People told us there are no guidelines based on evidence about how to treat mental health problems in autistic people.

We heard that there are no agreed standards of care within autism specific services.

## **Monitoring services**

Some autistic people and people with learning disability in hospital said they found it hard to tell someone when something happened to them, or they didn't tell someone when something happened because they were afraid that they would be punished if they did.

Some people said they felt listened to. Some people said they did not feel listened to.

Some carers told us that they did not feel involved in the person's care. They did not feel listened to. They felt as though their views were not taken seriously.

## **Monitoring decisions**

Some people said that the Mental Health Act gives a good framework for monitoring plans and how decisions are made.

The Act sets out when reviews should happen and how decisions should be made.

## **The Mental Welfare Commission**

Some people said that the Mental Welfare Commission are good at monitoring the Act.

If people are treated for mental illness and are not under the Act, they might not get the same amount of monitoring of their care.

Some said that the Mental Welfare Commission does not have enough power to make its recommendations happen.

## **The Tribunal**

Some people said the Tribunal does a good job of reviewing care plans and checking how decisions are made.

Some said that having a two year gap between reviews is too long.

Some people said that the Tribunal does not have enough power to help people get out of hospital.

## **Involving people with disability**

An organisation told us that people with learning disability have been involved in inspecting services.

Someone said there are not enough peer led autistic organisations. This makes it hard for autistic people to be involved in developing policy and services.

## Implementation and monitoring: Reports

Organisations of people with disabilities do not have enough support. They are not always involved as they should be when the government is working to implement human rights (2).

Services for people with disabilities are not always monitored effectively by independent authorities to prevent exploitation, violence and abuse (2).

Progress in getting rid of barriers to health care should be monitored, especially for the groups of people who the Mental Health Act applies to (2).

No one knows how many autistic people are under the Mental Health Act or in the mental health system. This makes it very difficult to know what is happening for this group of people (5).

Use of psychotropic medications and the effects of these medications is not consistently monitored for autistic people or people with learning disability as individuals, and is not monitored at all for these groups of people (5, 9, 10).

Monitoring and reporting of delayed discharges from hospital is not robust (4).

No one knows how many autistic people and people with learning disability have been found to have committed offences in Scotland (31).

The use of reasonable adjustments in the criminal justice system is not monitored for autistic people or people with learning disability (14).

<b>C</b>	<b>What we found</b>
	References for main reports

(1)	Coming Home: A report on out-of-area placements and delayed discharge for people with learning disabilities and complex needs Dr Anne MacDonald, Scottish Government, 2018	link
(2)	Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland United Nations Committee on the Rights of Persons with Disabilities, 2017	link
(3)	Am I there yet? The views of people with learning disability on forensic community rehabilitation Alana Davis, Michael Doyle, Ethel Quayle and Suzanne O'Rourke. NHS Lothian, NHS Fife and University of Edinburgh, 2015	link
(4)	No through road: people with learning disabilities in hospital Mental Welfare Commission for Scotland, 2016	link
(5)	Autism and the madness of the Mental Health Act Autism Rights, 2015	link
(6)	Assessment, diagnosis and interventions for autism spectrum disorders (SIGN 145) Healthcare Improvement Scotland, 2016	link
(7)	The Microsegmentation of the Autistic Spectrum: Economic and research implications for Scotland Tommy MacKay, Martin Knapp, James Boyle, Valentina Lemmi, Michael Connolly & Amritpal Rehill, 2017	link

(8)	Management of serious mental ill-health among people with learning disabilities in primary care: a comparison over time Scottish Learning Disability Observatory, 2017	link
(9)	People with Learning Disabilities in Scotland: 2017 Health Needs Assessment Update Report Dr Maria Truesdale and Professor Michael Brown, 2017	link
(10)	10 years of anti-psychotic prescribing in Scotland for people with learning disability Scottish Learning Disability Observatory, 2017	link
(11)	Autism and mental health: The views of people on the autistic spectrum on their mental health needs and mental health services Autism Rights Group Highland and Highland Users Group, 2011	link
(12)	Too complicated to treat? Autistic people seeking mental health support in Scotland Autistic Mutual Aid Society Edinburgh, 2018	link
(13)	Investigation into the death of Ms MN Mental Welfare Commission for Scotland, 2016	link
(14)	Monitoring the Implementation of the UNCRPD UK Independent Mechanism for the CRPD, 2014	link
(15)	What we talk about when we talk about investment in mental health Graham Morgan, The Lancet, 2018	link

(16)	Report to the Government of the United Kingdom on the visit to the United Kingdom carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 17 to 28 September 2012 Council of Europe, 2014	link
(17)	(Not a main report): Winterwerp v Netherlands The European Court of Human Rights, 1979	link
(18)	The exercise of legal capacity, supported decision-making and Scotland's mental health and incapacity legislation: working with CRPD challenges Professor Jill Stavert, Edinburgh Napier University, 2015	link
(19)	Partners in care?: views and experiences of carers from a cohort study of the early implementation of the Mental Health (Care & Treatment) (Scotland) Act 2003 Dr Julie Ridley, Susan Hunter and Dr Ann Rosengard, 2010	link
(20)	Are Mental Health Tribunals a good use of money? Learning Disability Alliance Scotland, 2016	link
(21)	Subjective experiences of compulsory treatment from a qualitative study of early implementation of the Mental Health (Care & Treatment) (Scotland) Act 2003 Dr Julie Ridley and Susan Hunter, 2013	link

(22)	Learning disability and the Scottish Mental Health Act Dr Heather Welsh, NHS Lanarkshire, and Dr Gary Morrison, The Mental Welfare Commission for Scotland, 2017	link
(23)	Citizens Grand Jury People First Scotland, 2011	link
(24)	Autistic son and mother flee UK Herald Scotland, 2012	link
(25)	Place of Safety Monitoring Report Mental Welfare Commission for Scotland, 2018	link
(26)	Disabled teenager was left without food or water in care home 'abuse' The National, 2016	link
(27)	Rights of People with Disabilities in Scotland: Submission to the United Nations Committee on the Rights of Persons with Disabilities 7th Pre-Sessional Working Group The Mental Health and Disability Sub-Committee of The Law Society of Scotland, 2017	link
(28)	Consideration of Petition PE1667: Calling on the Scottish Parliament to urge the Scottish Government to conduct a wide review of Scottish mental health and incapacity legislation and, when doing so, to take due account of recent developments in international human rights law Scottish Human Rights Commission, 2017	link

(29)	5 Year Survey of Need for Mental Health Inpatient Care for Children and Young People in Scotland with Learning Disability and/or Autism Dr Susie Gibbs, 2017	link
(30)	Supporting psychological wellbeing in adults with learning disabilities NHS Education for Scotland, 2017	link
(31)	The Criminal Justice Pathway for People with Learning Disabilities: Challenges and Opportunities for Change. Supporting Offenders with Learning Disability Network, 2015	link

We used two more reports in creating the ‘list of outcomes’. These reports did not tell us how well the human rights of autistic people and people with learning disability are protected and promoted, but they did suggest new outcomes to add to the list of outcomes:

Case Digest: Scottish Ministers v Mental Health Tribunal for Scotland (JK) Mental Health Tribunal for Scotland, 2011	link
G (AP) (Appellant) v Scottish Ministers and the Mental Health Tribunal for Scotland (Respondents) United Kingdom Supreme Court, 2013	link

<b>D</b>	<b>What happens next</b>
	What we will do next in the review

At the end of August 2019, we will tell people what we think might be needed in the law in future. This will be stage 3 of the review.

The information and ideas in stage 3 will be based on what we found in stage 2 of the review. You can tell us what you think of these ideas during stage 3.

Our final report and recommendations will go to the Minister for Mental Health in the Scottish Government in December 2019.