

Meeting the challenge

Guide 1:

Your rights when you are living in the community

Supporter version



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About these guides

This is one of two guides which outlines the rights of people with a learning disability when living in the community and their rights when in inpatient settings, like Assessment and Treatment units.

Guide 1 is about the rights of people with a learning disability **when living in the community**.

Guide 1 has an easy read version for people with a learning disability, and a version for supporters of people with a learning disability, which has more background about the issues raised in the easy read guide, so supporters can be prepared to answer questions and provide more information.

Guide 2 is about the rights of people with a learning disability **who are in Assessment and Treatment units**.

Guide 2 has an easy read version for people with a learning disability, and a version for supporters of people with a learning disability, which has more background about the issues raised in the easy read guide, so supporters can be prepared to answer questions and provide more information.

The development of these guides has been funded by the Department of Health through its Strategic Partners Programme.

Know your rights

The purpose of the guides is to help people with a learning disability, and the people who support them, know and understand their rights. We hope that if people know their rights, this will help them get the support they need in the community and reduce the number of people being sent to inpatient settings like Assessment and Treatment units.

Winterbourne View

Since the Winterbourne View abuse scandal in 2011, it has been a big concern that too many people with a learning disability are in inpatient units, like Assessment and Treatment units. The government and the NHS have recognised that changes need to be made to make sure that people with a learning disability can live full lives in the community.

Meeting the challenge

Your rights when you are living in the community

Guide 1: Supporter version

Introduction

This is **Guide 1**. It is about the rights of people with a learning disability **when living in the community**.

There are two versions of Guide 1.

An **Easy read version** and a **version for supporters**.

This is the **version for supporters**. It has more background about the issues raised in the easy read guide, so supporters can be prepared to answer questions and provide more information.

The rights of people with a learning disability who are in Assessment and Treatment units are covered in **Guide 2**. That has two versions as well.

This guide tells you about the rights of people with a learning disability when they **are living in the community**. 'Rights' are things that someone should get or that should happen.

Rights are very important. They help make sure a person can be safe and happy.

This guide should help you understand the rights of the person you support and what you or they can do if their rights are being ignored.

What is this guide about?

In 2011 a place called Winterbourne View was closed down after a television programme showed staff hurting the people staying there. The people all had learning disabilities and they were in Winterbourne View to get special care with their behaviour or mental health but instead they were being abused.

Winterbourne View was a special type of hospital called an 'Assessment and Treatment unit'. This means it was there to look after and treat people with a learning disability for mental health problems or if their behaviour was challenging, so that they could go home happier, healthier and safer.

Since Winterbourne View it has been made clear that too many people with a learning disability are being sent to Assessment and Treatment units. Lots of people are staying there for too long and are too far away from home.

This is happening because there is not the right support available in the community.

The government and NHS have said this must change. They have said the **right support must be developed in the community**.

They have said it is important people are only sent to Assessment and Treatment units if they really need to be there. And if they do need to go to one it is important they are:

- Only there for a short time
- Sent to one as close to home as possible
- Told what their rights are
- Treated in the right way

This guide aims to help you understand the rights of the person with a learning disability you are supporting, so that they can get the right services and support to meet their needs. This will help keep them safe, happy and healthy and make sure they know when things are not going the way that they should, so you both can take action to make things better.

Human rights

The Human Rights Act is a special law that sets out all of the rights that every person should have.

It says that everyone should have:

- The right to not be hurt by people or treated badly
- The right to be free – this means being able to live somewhere that you choose to and be able to leave your home and go out
- The right to be safe
- The right to a family life – this includes being able to talk to your family, write letters to them and see them
- The right to be able to be yourself and make decisions for yourself.

(Note: these rights are called ‘qualified’ rights, which means there are circumstances in which interference with these rights can be justified by the State).

The Human Rights Act helps to make sure that your basic rights are met.

The Human Rights Act should be followed by the people who care for you and look after you. Knowing what the Human Rights Act means is important to make sure you know when you are not being treated in the right way.

To find out more about the Human Rights Act see the Equality and Human Rights Commission’s booklet ‘Ours to own: your human rights’:

www.equalityhumanrights.com/sites/default/files/documents/publications/ours_to_own_easy_read.pdf

What other laws do you need to know about?

The Mental Capacity Act

The ‘Mental Capacity Act’ is another important law that is there to help make sure people with a learning disability get the support they need to make their own decisions. Where they are not able to make their own decision, a decision is made in their ‘best interests’.

The Mental Capacity Act says that people should always support a person to make their own decisions if they can. This might mean giving them easy read information or explaining something in a different way.

But if a decision is too big or complicated for a person to make, even with support, then people supporting them must work with the person and their family to make a ‘best interests’ decision for them. This means they make a decision that is the right one for the person with a learning disability. They must involve the person as much as possible in working out what the right decision is.

Just because someone is not able to make one decision, this does not mean they can’t make other decisions. People should always support a person to make their own decisions if they can do so.

What is a person's 'best interests'?

Making a decision in someone's best interests means the people around the person make a decision that they believe is the right one for them. When making a best interests decision, the person making the decision, for example a social worker or GP, must listen to the person with a learning disability, their family and supporters.

If they have a meeting to discuss this (a 'best interests' meeting), the person with a learning disability, and their family have a right to be there.

What if the person concerned, or their family, are not happy with the decision?

A person with a learning disability, or their family, have the right to challenge a best interests decision if they do not think the decision made is really in the person's best interests. There are various things that can be done, for example:

- Ask for an advocate to be involved
- Ask for a second opinion
- Make a complaint.

If none of these things work, and there is still a disagreement, the **Court of Protection** could be asked to decide the matter.

For more information about the Mental Capacity Act 2005, see the Local Government Association, NHS England and the Care Provider Alliance's easy read guide:

www.local.gov.uk/documents/10180/12137/ntal+Capacity+Act+2005+easy+read+guide/38683f88-4b96-49d6-86ab-89b2404d2e7a

Good Support

What is Good Support?

Good Support means that you are getting the support that you need to live a safe and

healthy life.

A person might need:

- **Support from a support worker** for things like personal care or managing bills or for activities
- **Support to stay healthy**
- **Support for behaviour** for example when they get upset or anxious their behaviour might get challenging
- **Support from an advocate** to help get their voice heard and be included.

How to get support

If someone thinks they need support, they should talk to a social worker or someone else at their local council. An advocate (if they have one) or family or friends should be able to help too.

The social worker must carry out an 'assessment' to look at what needs a person has. It is important the person being assessed is fully involved in this and gets the support they need to be fully involved.

The social worker should give the list of questions that will be asked in the assessment, beforehand. The list should be given to the person being assessed in a way they understand.

The person doing the assessment must have the rights skills and knowledge to carry out the assessment. It is important all the needs of the person being assessed are looked at so they end up getting the right support. If the person you are supporting has health or behaviour needs, you should ask for professionals with the right skills to be involved.

If the social worker says a person's needs are high enough to be able to get support - this is called having 'eligible' needs. 'Eligible' needs have to be met. If they are not being met it is against the law.

Care and support plan

If a person has eligible needs, professionals will then work with them on a 'care and support' plan, a plan which sets out what services will be

provided, how these services will meet the person's needs, who will provide them and how often.

At the bottom of the care and support plan there will be a sum of money, called a personal budget.

The amount must be enough to meet 'eligible' needs and pay for all the services set out in the care and support plan.

There are different options for how the personal budget can be used:

- The local council could provide services for a person.
- Another organisation could provide the services.
- The individual could get a direct payment (cash payment) to buy the support or services they want.

Or a combination of these.

Can people with a learning disability always get a personal budget?

If a person's support is **funded by the local council**, they will get a personal budget to meet their 'eligible' needs (it will be at the bottom of the care and support plan).

There is a right to request a direct payment (cash payment) to buy the support or services a person wants. And the council must say yes to this in most circumstances.

If a person's support is **fully funded by Health (NHS continuing healthcare)**, then they have a right to request a personal health budget.

A person can ask for a direct payment (cash payment) to buy the support or services they need. This request must be granted unless the health body assesses that it would be inappropriate.

Where someone has a **joint package** – where their support is funded by the local council and health, they can ask for a personal budget.

Getting support to speak up

An advocate is someone who can help a person speak up and tell people what they think. They can also speak up for people where they find it hard to do so themselves.

If someone needs support to take part in the assessment or in the care and support planning - and it would be really difficult for them to take part without support - the local council must provide an advocate (if the person does not have family or a friend to support them).

People with a learning disability might want an advocate to support them at other times. If so, they should speak to a social worker, care manager or someone else they trust to see if this is possible and ask them to help find an advocate.

Find out more about assessments, care and support plans and advocates, in the Department of Health's easy read document about the Care Act 2014:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/365345/Making_Sure_the_Care_Act_Works_EASY_READ.pdf

Other things that can help make sure you get good support:

A **person centred plan** - this can help show others what is important to a person, their hopes and goals, and what they might need support for.

A **communication passport** - this is a document which explains how a person communicates and some of the things that are important to them.

A **health check every year** - this is where a person sees their GP every year for a full check of their health. If they are not getting one, they should ask their GP for one.

A **health (hospital) passport** - this explains important health information about a person, for example, if they are on medication or if they have any conditions, such as diabetes. It also says how they communicate. It can be used in places like hospitals to help make sure a person gets good support.

A **health action plan** - tells a person what they need to do to keep healthy. It tells them what services and support they need to live a healthy life.

If the person you are supporting does not have these things, they should be supported to get them. Family members, advocates, social workers or a GP can all be of help.

Find out more about health (hospital) passports, health action plans and health checks on the Easyhealth website:

www.easyhealth.org.uk

Support with behaviour

If a person thinks they need support with their behaviour, they should be supported to ask their social worker or GP if they agree support is needed. There should be professionals, like psychologists or nurses in the community who can help. Sometimes they will be in a team called the Community Learning Disability Team or Crisis Support team. It is important they know about supporting people with learning disabilities who show challenging behaviour, including about something called 'positive behaviour support'.

They work with people to try to understand the causes of behaviour. They should draw up a 'behaviour support plan' which explains what support a person needs to help manage their behaviour. The person themselves should be involved in making this plan as well as other people who know them well.

Sometimes a person's behaviour can get

challenging because they are not living in the right place - for example, if they are living in a place that is too noisy. Or it might be because they are not being supported by someone with the right skills, for example someone who doesn't understand their way of communicating. If someone thinks the place they live in, or the support they get isn't right, they should talk to an advocate (if they have one), a social worker/ their care manager, their family or someone who supports them. This should be something that is discussed in an 'assessment'.

How to know if support is good

To get good support the right things need to be in place to keep a person happy, healthy and safe. If a person doesn't feel safe, happy or healthy something might need to change.

If the person you are supporting is worried they are not getting the right support, they can talk to:

- Family members
- An advocate (if they have one)
- A social worker/ care manager.

They should be able to help with the next steps, for example:

- asking for another assessment (called a 'reassessment') - this may result in getting more support or different support that suits someone's needs better
- making a complaint if necessary or getting some advice from a lawyer.

The person I support has been told they must go to an 'Assessment and Treatment unit'

If someone is told they need to go to an Assessment and Treatment unit to get the right support or treatment, it is important to ask if all options have been looked at to get the support in the community first. People should only have to go to a unit if it is really necessary.

If someone is told they have to go into a unit this is called 'detention' or being 'sectioned'.

Read the Mental Health Act Code of Practice Easy read factsheet on 'Detention and your rights':

www.nhs.uk/NHSEngland/AboutNHSservices/mental-health-services-explained/Documents/easy-read/MH-CoP-Being-detained.pdf

If someone is told they have to go to an Assessment and Treatment unit but they or their family don't think they need to go, they should get some advice from a lawyer.

This should be a lawyer who:

- Understands the Mental Health Act
- Understands about Community Care law – so they understand about getting the right support in the community
- Understands the Human Rights Act
- Understands the needs of people with a learning disability

What should a person do if they experience abuse?

The people at Winterbourne View experienced abuse. It is important the person you support knows what to do if they are being abused.

What is abuse?

Abuse is when a person is treated badly by someone. This could happen anywhere. It might be by someone a person lives with, someone who supports them, a friend, family member, or someone else.

Nobody should be abused and it is against the law.

There are different types of abuse. Abuse includes things like:

- being hit or hurt by someone
- being called names or victimised

- being forced to have sex with someone or do sexual things that a person does not want to do
- having money or belongings stolen
- having health or care needs ignored by those who are meant to be caring for a person.

If the person you support is worried that someone is treating them badly they should make sure they talk to someone about it.

Getting help?

There are lots of ways to get help if someone is being abused or thinks they might be.

If they are being abused now:

- they should talk to someone they trust. This might be a family member, advocate, a service manager, social worker or someone else
- they should explain to them what has happened and ask them to help
- the social services 'Safeguarding Team' should be called, who are there to make sure people are safe.

If someone is ever in **immediate danger** they should contact the police.

If someone has been abused before:

There are lots of ways a person can get help if they have been abused before:

- they could talk to someone they trust. This might be a family member, advocate, a service manager, social worker or someone else
- they could talk to their GP about seeing a counsellor
- they could talk to a charity called **Respond** who could help get the right support
- they could report it to the police
- they could talk to a lawyer.

If the person you support has not already told someone about what has happened it is not too late for them to speak to someone and get help.

Remember: no one should have to face abuse – it is not allowed and is against the law.

See Change's 'What is safeguarding?' easy read document:

www.changepeople.org/blog-and-news/what-is-safeguarding-easy-read-guide-from-change-updated-2015/

See BILD's webpage on easy read information about Keeping Safe:

<http://www.bild.org.uk/easy-read/easy-read-information/keeping-safe-easy-read-information/>

See The Ministry of Justice's 'The support you should get if you are a victim of crime' easy read document:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/264850/easyread-victims-code.pdf

Respond – a charity that works with children and adults with learning disabilities who have experienced abuse through psychotherapy, advocacy, campaigning and other support. They offer support to families through their family support service.

www.respond.org.uk

For more information

Meeting the challenge guides for families:

www.mencap.org.uk/meetingthechallenge

Meeting the challenge frequently asked questions about the law

www.irwinmitchell.com/meetingthechallenge

Do a person's rights ever change?

Rights can change at some times like if a person is sent to an 'Assessment and Treatment unit.' In this case, rights would be a bit different. Look at Guide 2 for more information on this.

Rights might also change if a person is arrested and gets sent to an 'Assessment and Treatment unit' because of this.

People with a learning disability have the same human rights as everyone else and should always be treated in the right way.

For more information visit
www.mencap.org.uk/meetingthechallenge

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Charity number 222377 (England, and Wales); SC041079 (Scotland) 2014.106

