

Improving Care Improving Lives

What is it like for people with a learning disability who are getting care through hospital?

This document was written by the **NHS Wales National Collaborative Commissioning Unit**. It is an easy read version of the “**National Care Review of Learning Disabilities Hospital Inpatient Provision Managed or Commissioned by NHS Wales**”.

February 2020

How to use this document



This is an easy read version. The words and their meaning are easy to read and understand. You may need support to read and understand this document. Ask someone you know to help you.



Words in **bold blue writing** may be hard to understand. They have been explained in a box beneath the word.

If the hard word is used again it is in **normal blue writing**. You can check what the words in blue mean on **page 32**.



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Introduction by Joe Powell



This is an important piece of work. It shows us what the main issues are when we are treating patients with a learning disability.



It is not ok that some people with learning disabilities have been living in places like hospitals for a long time.



People with learning disabilities used to live in hospital all their lives. We are trying to move on from this.



We have made a lot of good changes in the way we support people with learning disabilities.



Most people with learning disabilities live in the community and are supported in a way that is best for them.



But it seems like people with learning disabilities are sometimes left behind when it comes to physical health.



I want this work to help everyone know about these problems.



I want Welsh Government and all health organisations to work together to make things better for patients with learning disabilities. And to protect their human rights.



Joe Powell
Chief Executive, All Wales People First

About this work



The Welsh Government has a programme called **Learning Disability Improving Lives**.



It is supposed to help people with a learning disability to live **independent** lives. And avoid staying in places like hospital for too long.



Independent means doing things for yourself and making your own decisions.



This work looked at people with a learning disability who need health care and treatment given by hospital services.



They need to live in hospital, or places like hospital when they are getting their treatment. They are living in places like:



- **Secure hospitals.** These are hospitals where patients are locked in. Staff have special training to keep patients safe.



- **Assessment and treatment units.** These are places where patients can be seen quickly. And get treatment for serious health problems. The doors are locked to keep people safe.



- **Residential care homes.** These are homes where people can also get personal or nursing care. People living in these places have their own bedroom. They will share the home with other people who have similar needs.



Even if they live in the community people with learning disabilities sometimes need to get treatment through hospital.



When they do they should be treated in a way that works for them. This is their right.



In February 2019 the **Chief Nursing Officer** asked us to check how we care for people with learning disabilities.



We found that there are many issues we need to take care of straight away. This document is about what we learned.

What we learned in numbers



We looked at **166** patients with a learning disability for this work. Every one of these patients is important. They all deserve good, safe care.



114 of the patients were men.



52 of patients were women



The youngest patient was **18**



The oldest patient was **83**



Most patients were aged around **43**



Most patients spent just over **5 years** in a place like a hospital



139 of the patients showed behaviours that challenged



All **166** patients had hospital support plans



130 patients had care plans



150 of the patients were given medicine to control their mood and the way they behaved.



It costs over **£33 million** a year to pay for the cost of care for these 166 patients.

Making sure patients get the right care



If patients get the right kind of care for them, they are less likely to have to stay somewhere like a hospital.



They are also more likely to have a better experience.



We should train staff to understand people's different needs. And to notice problems so they can stop them before they happen.



We should also make places like hospitals safe for patients. And design them in a way that meets their needs.



There are some groups we especially need to think about.



Older people

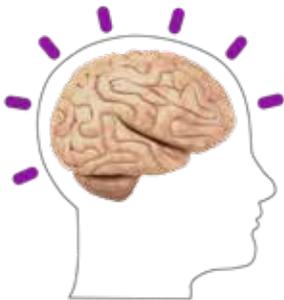
People with a learning disability are living longer than before.



This means that there are more older people with a learning disability who need care and support. And they have needs that are different to other patients.



For example people with a learning disability are more likely to develop **dementia** as they grow older.



Dementia is a condition that affects the brain. People with dementia have problems with memory and can be confused. It usually affects older people.



Small changes like putting handrails in corridors and making bathrooms more **accessible** will help these patients to have a better experience.



Accessible means everyone is able to get to them and use them easily.



Male and female patients

We have found that male and female patients with learning disabilities also have different needs.



This includes their physical health and their mental health.



Staff need to know what these differences are to support patients in the right way.



Diagnosis



We found that many patients with a learning disability who are getting care through hospital also have another **diagnosis**.



A **diagnosis** is when a doctor looks at your health and behaviour and decides if you have a condition or not.

This can be things like:



- autism

- **dementia**



- mental health conditions.



We need to think about these other **diagnoses** when we plan our learning disability services.

Listening to what patients think



If we want to give the right kind of care we need to listen to what patients say.



When we did this work we asked patients what they thought about their care.



In general people said good things about their care. But they also said that they would like some things to be different.



Health care providers should keep asking patients how things could be better for them. And include them when they are planning services.



They should keep a record of how happy patients are with their care. And use this to check that they are always improving.

“Going home to visit Mum.”

What one patient said when we asked what was important to them in hospital

“Do more things with staff.”

What one patient said when we asked what they would change in hospital

“To get out.”

What one patient said when we asked what was important to them in hospital



Making sure patients do not stay in hospital for too long



We have found that many patients with a learning disability have long stays in places like hospitals.



People with a learning disability should only have a stay in places like hospitals if there are no other ways to treat them safely.



Health care providers should have a clear goal for the person's treatment. Like:



- Helping people to behave in a way that does not harm themselves or others.



- Helping the patient to be more **independent**.



- Helping the patient to deal with difficult things in a better way.



- Lowering the amount of medicine the patient needs.



- Helping the patient with serious mental health problems.



Patients who have been in places like hospitals for many years can get used to living there. After their long stay they can find it hard to live in the community. We do not want this to happen to anybody.



We want patients to live at home if they can. And we want to help people stay at home before they need to get care through hospital at all.



We should think about the people who are most likely to need hospital care and try to support them.



If the right kind of support is available in the community, people are less likely to have a long stay in somewhere like a hospital.

Following the law and respecting people's rights



A lot of the time when people go to a place like hospital they agree to be there and get treatment. But sometimes people are **detained**.



If someone is **detained** it means they are kept in the place they are getting hospital care. They have to stay and get treatment even if they do not want to be there.



This can be because they are having mental health problems and professionals think they could hurt themselves or other people if they do not get treatment.



Or it could be because they need treatment but are not able to agree because of their learning disability.



We must make sure that all patients who are **detained** know their rights. This is the law.



We must check often that patients who are **detained** need to be in a place like hospital.



We also must check if a patient is able to agree or not. If they are getting therapy they might be able to agree when they could not before. So we must always check.



Making sure we use medicine properly



Medicine can be an important part of a patient's treatment.



But we should not use it as a quick fix when a person might need long term therapy and support.



Patients are being given more medicine than expected, to change their moods. And stop them from behaving in a challenging way.



Staff are also giving people with a learning disability medicine for mental illness. Even if they do not have a mental illness.



This is a **restrictive practice** and we should try not to do it.



A **restrictive practice** is a way of stopping people from doing what they want to do. Or controlling people.



If a person is struggling with behaviour that challenges we should first try to calm them down with **positive behavioural support**.



Positive behavioural support is about understanding why a person behaves in a challenging way.



There is usually a reason or problem that causes someone to behave in a challenging way. **Positive behavioural support** tries to sort out the problem.



If we have to use medicine to calm somebody down we should watch them carefully to see that the medicine does not harm them.



We should only carry on using medicine that has a good effect on the person's health.



And we should try and use medicine for as short a time as possible. So that the person's body does not get so used to the medicine that they cannot cope without it.

Working with behaviours that challenge

Behaviours that challenge can include lots of different things. Like:



- Making threats.
- Hurting other people or putting yourself in danger.
- Breaking things.
- Behaving in a sexual way when it is not ok to do so.
- Running away.



People can have behaviours that challenge for many reasons. Like:



- Finding it hard to communicate.



- Feeling bored or angry.



- Feeling upset and worried.



- Struggling with physical or mental illness.



We found that supporting patients with behaviours that challenge can be very stressful for staff. We need to look after our staff's **well-being**.



Well-being is anything to do with your health and happiness.



We should also try and help patients before they have behaviours that challenge. We should do this by:



- Making places like hospitals as safe and nice as possible.



- Training staff to notice the early signs of behaviours so they can stop them from happening.



We should make sure we have enough staff to manage behaviours when they happen. And that they have the skills and experience they need.



We should also make sure we keep checking if a person is at risk. And keep them in places like hospital for as short a time as possible.

Lowering the use of restrictive practices



Restrictive practices can be used when they are in a patients' **hospital support plan**. And when there is no other way to keep them safe.



A **hospital support plan** is when we write down how a person will get the medical treatment they need.



The **hospital support plan** must say clearly why **restrictive practices** are needed.

There are different types of **restrictive practices**. For example:



- Giving medicine to control mood and how someone behaves.



- Rules about when you are allowed to go to certain places, like your bedroom.



- Only being allowed your mobile phone at set times.



- Not having total control over how you spend your own money



128 of the patients we looked at for this review had at least 1 **restriction** put on them.



The most used **restrictive practice** was not giving people total control over how they spend their money.



We should only use **restrictive practices** to keep people safe. It should never be used to punish or embarrass someone.



If we have to use **restrictive practices** to keep people safe we must:



- Use the least force possible.



- Use them for the shortest amount of time possible.



- Treat the patient with respect.



- Write down everything that happened.



We know that we cannot stop using **restrictive practices** completely. But if we care for people in a way that is right for them, they are less likely to need them.

Using care plans and hospital support plans



Every patient with a learning disability should have a **care plan** and a **hospital support plan**.



A **care plan** is when we write down what a person will get the care they need.



Both plans should be written with the patient and help them to take control over their own support.



We should check **care plans** at least every 6 months and keep them up to date. We should check **hospital support plans** at least every 3 months.



If a person wants to be supported in a different way we should change the plan to show this.



All plans should focus on what the patient and their family think is important. And they should have clear goals about the person's care and treatment.

Caring for people in the community



Hospital care should help patients get ready to live in the community. And to have more **independence**.



Moving from places like hospitals back to the community can be scary and hard for patients.



We should plan this move with patients as well as their carers and community services. And we must understand that some patients will feel that the hospital is their home.



We can support the patient to visit their local area so they can get used to it.



The patient can also try going back home or into community care for overnight stays.



We have to think about any risks there might be to the patient or to others.



And we have to think about what will help the patient to get better.



Community services are very important for people's **well-being**. We believe Welsh Government should make sure money is spent on improving community services.



Supporting people with a learning disability to take care of their health



People with learning disabilities are more likely to have health problems that can be avoided.



This is because some people can find it hard to visit the doctor or remember appointments. Or they might find certain things like tests stressful.



Every person with a learning disability has the right to have a health check every year with their doctor. But half of people with a learning disability do not go to their health check.



Welsh Government wants to help more people go to their health check. And to help them have a better experience when they are there.



If we help people with learning disabilities take care of their health at home they will be less likely to have serious health issues. And they will be less likely to have to spend time in places like hospital.

Hard words

Accessible

If something is accessible it means that everyone is able to use it easily.

Care plan

A care plan is when we write down how a person will get the care they need.

Dementia

Dementia is a condition that affects the brain. People with dementia have problems with memory and can be confused. It usually affects older people.

Detained

If someone is detained it means they are kept in hospital. They have to stay and get treatment even if they do not want to be there.

Diagnosis

A diagnosis is when a doctor looks at your health and behaviour and decides if you have a condition or not.

Hospital support plan

A hospital support plan is when we write down how a person will get the medical treatment they need.

Independent

Independent means doing things for yourself and making your own decisions.

Positive behavioural support

Positive behavioural support is about understanding why a person behaves in a challenging way.

Restrictive practices

A restrictive practice is a way of stopping people from doing what they want to do. Or controlling people.

Well-being

Well-being is anything to do with your health and happiness.