

Easy Read



Llywodraeth Cymru
Welsh Government

How we deliver autism services in Wales



This document was written by the **Welsh Government**. It is an easy read version of 'Code of Practice on the Delivery of Autism Services'.

July 2021

How to use this document



This is an easy read document. But you may still need support to read it. Ask someone you know to help you.



Words in **bold blue writing** may be hard to understand. You can check what all the words in blue mean on **page 42**.



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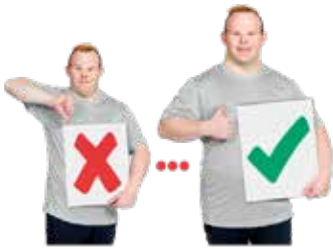


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Introduction



We want to make autism services in Wales better.



We have written this **Code of Practice** to say how autism services should work. And what types of services should be available.



A **Code of Practice** gives rules and advice about the best ways of working. It explains how to follow laws and plans. We will call it the **Code** for short.



All local authorities, and local health boards and **NHS trusts must** follow this **Code of Practice** by law. It says what they **must** do to help autistic people.



NHS trusts are organisations like the Welsh Ambulance Service and Public Health Wales.

This **Code** is for:



- Autistic people – so they know what services they should get.



- Autism service providers.



- All staff who support autistic people and their families and carers. Like health and social care staff and teachers.



- People who plan, organise and pay for autism services.



- All people, whatever age they are.



This **Code** will help local authorities, health boards and **NHS trusts** understand what different laws say they **must** do to help autistic people. These laws include:

- **Social Services and Well-being (Wales) Act 2014**
- **National Health Service (Wales) Act 2006**
- **Additional Learning Needs and Education Tribunal (Wales) Act 2018**
- **Mental Health Act 1997**
- **Mental Health Wales Measure 2010**
- **Well-being of Future Generations (Wales) Act 2015**
- **Equality Act 2010**
- **United Nations Convention on the Rights of the Child**



The **Code** is split into 4 sections that explain how autism services should be organised.



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Welsh Government has the power to tell local authorities, local health boards and **NHS trusts** what to do, to make sure they are following this **Code**.



Local authorities, local health boards and **NHS trusts** must write a report each year for Welsh Government. The report will explain how they are making sure they follow this **Code**.



The **Code** will use “**Autistic Spectrum Condition (ASC)**” as a definition of autism.



The **Code** will say “**autistic people**” instead of “people with autism”. People have told us they prefer this.

1. Assessment and diagnosis



This section is all about how people who might be autistic can get:

- an autism **assessment**
- a **diagnosis**
- support when they are going through an **assessment**.



An **assessment** is a set of questions and tests that can be done to see if a person may be autistic, or to see if they need care and support.

A **diagnosis** is when health professionals look at a person's health and behaviour to decide if they have a condition or not.

Getting an assessment and diagnosis



Health and social care staff should know what the signs of autism are. They should have training on this and know how to refer people for an **assessment**.



They should give information to the person and their family or carer to explain what will happen next.



There must be an agreed way of working across Wales. Autism **assessments** should be the same wherever you are in Wales.



People must be able to refer themselves or the person they care for. Health and social care staff must listen to their views.



People must be offered support when they are waiting for an **assessment**. If it is decided that you do **not** need an **assessment** the reasons should be clearly explained to you.



Children and adult services must work alongside each other. **Assessments** for children and adults should happen in a similar way.



People in places like prison must be able to get an autism **assessment** and support, if they need it.



Assessments should be done within a set amount of time. You should not have to wait too long.



The results of your **assessment** should be explained clearly to you in person.



If you are **diagnosed** with autism you must be offered a follow-up appointment within 6 weeks. You should also be told how to get further support.

Duties for assessment and diagnosis

Local authorities must:

- Make sure people with autism know they have the right to a **needs assessment**. And their carers have the right to a **carer's assessment**.

A **needs assessment** is when health and social care staff find out what your needs are and how they can support you.

A **carer's assessment** is when health and social care staff check what your carer's needs are and how they can support them.

- Make sure it is clear how people can get an **assessment**.



Local health boards and NHS trusts must:



- Give people **assessment** and **diagnosis** services. And follow the guide for the best ways of doing this.

- Make sure health staff like GPs know how to refer people for **assessment** and **diagnosis**.



- Make sure people do not wait too long for an **assessment**.

- Give people **diagnosed** with autism another **assessment** if needed, to see what support they need. People must agree to this first.



- Refer people **not diagnosed** with autism to social care services for an **assessment**, if they need care and support. People must agree to this first.



- Make sure autistic people can easily get support services for other conditions. For example mental health problems or learning disabilities.

- Make sure people in places like prison can get **assessed** and **diagnosed** for autism if needed. Make sure staff in these places understand when someone might have autism.

Local health boards, NHS trusts and local authorities must work together to:



- Meet the needs of autistic people who have extra support needs. For example people who have autism **and** mental health problems or learning disabilities.



- Work together and share information about the needs of autistic children and adults.



- Share information about the needs of people who do **not** get **diagnosed** with autism, if they still need care and support.

- Make sure people in places like prison can get **assessments** and social care support.



- Put someone in charge of organising and checking how people get **assessments** and **diagnosis**.

2. How people get health and social care support

This section is about:



- How people get different support services. Like health, social care, and mental health services.



- How local authorities, local health boards and **NHS trusts** should meet the needs of autistic people.

Getting health and social care services



People should be able to get information that helps them get help and advice. They should get this in a way that makes sense to them.



Services should work together so people get the support they need in the best way.



People must feel they can have an equal say in their care and support. Autistic people can ask someone to support them during the needs **assessment** and all appointments.



They can ask a family member, friend or **advocate**. Your local authority must help you get an **advocate** if you want one.



An **advocate** is someone who can help you speak up for yourself and make sure your views are heard.



Local authorities **must** provide different services that can stop problems happening or getting worse. These services are called **preventative services**.

Eligibility and IQ



Eligibility is when there is a list of things you need to have to be able to get support. You are **eligible** for support if you have something on the list.

IQ is a score that says how intelligent or clever someone is.

Eligibility must be based on:

- Your situation.
- What your wants and needs are.
- What might be stopping you getting what you want and need.
- Any risks to yourself or others.
- What your strengths and abilities are.





Staff doing needs **assessments** must understand how autism can affect a person's life.



Eligibility has nothing to do with your **IQ**. **IQ** should not be thought about when deciding if you need an **assessment**.

Assessments for care and support from your local authority



If you have care and support needs, you have a right to an **assessment** of those needs.



The **assessment** should help us better understand your needs. And decide the best way of supporting you. This will be done by making a plan.



Sometimes when people have a lot of needs it takes more work to do a full and proper **assessment**. But it should not take longer to get support because you have a lot of needs.



You should be told how long the **assessment** will take and what is happening.



Carer's assessments can happen at the same time as **needs assessments** if this helps you and your carer.



Social care staff must understand the needs of autistic people. So they can give the best advice and support to parents and carers.



You should be asked about your communication and language needs. For example, you may prefer to speak in Welsh. Or have written information in easy read.



Staff must record if you have needs that they cannot meet. This should be used to improve services in the future.



If you do have needs that your local authority is responsible for, they must write you a care and support plan.

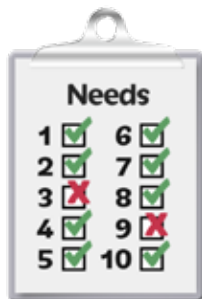


Care and support plans must say:

- what you want to achieve through your care and support plan



- what the local authority must do to help you achieve what you want



- what your needs are



- how we will keep checking if your plan is working for you



- the date we will next check your plan.



If your situation or needs change your plan must be checked and changed if needed. Any changes in your life should be planned carefully. You should be given support to manage these changes.



Before your plan is closed, we must check how it has worked for you.



You may be able to use **direct payments** to organise your care and support.

A **direct payment** is money you can be given instead of a service. You can use it to buy your own support and services.



Your local authority must give you information about **direct payments** to help you decide if you want to use them.



Local authorities must support you to use **direct payments** if that is what you want.

Transition



If changes happen in your life, you should be given support to manage these changes. And have another **assessment** of your needs.



Autistic people can also ask for a review when changes happen. Changes could include leaving school for further education or other services.



Autistic children and young adults going through life changes must be able to get support that is close to where they live.



The support must be provided by the service most suited to their needs. And it should be given until life has settled again.



Support should be given as early as possible. Services need to focus on giving early support. This will help autistic children feel empowered and able to become adults in the way they choose.

Carer assessments



It is very important that the people who carry out social care **assessments** understand the needs of autistic people. This will allow them to give the best advice and support to parents and carers.

Health care



All health services and staff must think about the needs of autistic people and make **reasonable adjustments**.

Reasonable adjustments are changes we can make to make sure everyone is able to use services. For example giving extra time for appointments. Or giving information in easy read.

Support for people in prison

Local health boards, local authorities and prison services must work together to:

- Support autistic people and make **reasonable adjustments**.
- Give staff training on autism.



Other support services



Autistic people have the right to other health services if needed. For example mental health services and education.



All services must make **reasonable adjustments** for autistic people. If possible, staff who have experience of autism should be involved in their care and support.



Staff should get training on autism if they are likely to work with autistic people.



Schools must have support services for autistic children.



Autistic adults who have social care needs must have support which meets their needs.

Duties for health and social care services

Local authorities must:



- Make sure people can get information about autism services in their area.
- Make sure that a person's **IQ** is **not** used to decide if someone can have a **needs assessment**.
- Make sure staff involved in social care **assessments** understand how autism can affect a person's life.



Local health boards and NHS trusts must:



- Make sure health staff like GPs know about autism services in their area. And how people can get these services.



- Make sure staff get training in autism, behaviours and needs.

- Make sure **IQ** is **not** used to decide if someone can have a **needs assessment**.



- Make sure autistic people who also have other conditions can still use **Children or Adults Mental Health Services (CAMHS)**. **CAMHS** must think about how autism may impact an individual when planning care and support.

Local health boards, NHS trusts and local authorities must work together to:



- Make sure autistic people and their carers know they both have the right to a **needs assessment**. This should be offered when they have been **diagnosed** with autism.



- Make sure people are not refused other support and services because they are waiting for their **diagnosis**.

- Make sure services make **reasonable adjustments** for autistic people. So they can get services in the same way as everyone else.



- Make sure autistic people in places like prison can get health and social care from staff who have had autism training.

- Help services to find new ways of working.



- Make sure specialist services are available when needed.

3. Raising awareness and training



This section is about:

- making sure everyone understands autism and how that impacts someone's life



- making sure that staff working in services can get and use knowledge and skills to provide services and support for autistic people, their families and carers.

The Equality Act 2010



This law says that services have a duty by law to make **reasonable adjustments** for autistic people.



Services need to think about what kind of **reasonable adjustments** they could make before they are needed.



Local authorities and local health boards must make sure autism training includes making **reasonable adjustments**.



Services must make sure they give information in a way that people can understand. They must provide a special **advocate** or **interpreter** to help with this if needed.

Helping communities understand autism



We need to make sure autistic people are included in their community. To help with this we need people in communities to understand autism.



Local authorities and other providers must make sure they meet the needs of autistic people. They can do this through things like:



- Supporting autistic people and their families and carers to take part in activities.



- Giving information about autism, rights, training and what is happening in the area.

Training for health and social care staff



All staff should understand how they can make small changes to the way they work to support autistic people.



Local authorities and health boards must make sure their staff have the right skills to support autistic people.



They should check what training their staff need. And organise good, on-going training to meet those needs.



Some health and social care staff who work directly with autistic people should have a higher level of training.



This includes people who do **assessments**, care for and treat autistic people. For example:

- Dentists
- Teachers
- Doctors
- Firefighters
- Hospital staff and volunteers
- Social workers



Local health boards and **NHS trusts** must make sure autistic people are not stopped from getting services or support because they are autistic.



They must do everything they can to help autistic people understand their treatment while in hospital.



Training must be updated often.



Local authorities must make sure that community social care staff get the right level of training in autism.



Schools and colleges should have a specific person with the right level of training to meet the needs of autistic people.

Duties for raising awareness and training

Local authorities must:



- Make sure staff who carry out **needs assessments** have the right skills to do it. If they do not they must get advice from someone who does.



- Make sure the **Information, Assistance and Advice Services**, that local authorities provide, give information about autism services in their area. This is a service for everyone. It gives people a main point of contact if they need help getting care and support services.



- Make sure social care workers have the right qualifications to do their jobs.



- Make sure all staff have the right training and skills.

Local health boards and NHS trusts must:



- Make sure health care staff have the training and information they need to do their jobs.



- Make sure everyone doing **assessments** has the skills and information they need.



- Make sure health staff like GPs know about autism services in their area. And how people can get these services.

Local health boards, NHS trusts and local authorities must work together to:



- Include training on autism in equality and diversity training for all health and social care staff.



- Check what autism training health and social care staff need for their different jobs.



- Make sure staff know about the **Information, Advice and Assistance Service**. This is a service for everyone. It gives people a main point of contact if they need help getting care and support services.

- Make sure staff can get the right information, resources and training on autism. And make sure this is kept up-to-date.



- Make sure autistic people, parents and carers are involved in autism training. They can help to plan or give the training.

4. Planning and checking services and involving people

This section is about:



- how local authorities and health boards plan and run services to meet the needs of the people in their area



- how **Regional Partnership Boards** must make sure local authorities, local health boards and other partners work together to deal with the **population needs assessments**. And deliver the area plans.



Regional Partnership Boards are made up of staff from local authorities, local health boards, other partners and people. They work together to make sure health and social care services in their areas are planned well.

The **Social Services and Well-being (Wales) Act 2014** says local authorities and local health boards must work together to do a **population needs assessment**.

This is when they gather information to find out what the care and support needs are of the people living in their area.

Population needs assessments



Local authorities and local health boards must work together to do a **population needs assessment**. They will do this every 5 years to see:

- How people's needs are not being met.
- What services are needed to meet people's needs in their area.
- What services are needed to stop problems from happening. Or stop them getting worse.
- How services can be given in Welsh.



The **population needs assessment** must be specific to autism.



They must write a report about what they learned from the **population needs assessment**. Everyone living in the area should have a say in gathering information for the report. Reports must be written every 5 years.

Area plans



Regional Partnership Boards should make sure local authorities and local health boards work together to write an **area plan**.



The area plan says how they will meet the needs of people in their area.



The **Regional Partnership Board** will check the area plan each year. This will include checking autism services.



They will check to see if their autism services are following the Welsh Government plan for autism.

Collecting information and checking services



Local authorities and health boards will collect information about people with autism and services in their area.



This is to help plan services. This information is kept safe and private.



Each **Regional Partnership Board** should choose 1 person to be in charge of collecting information. And checking that autism services set out in the area plans are being delivered.



They should also make sure autistic people and their families and carers are fully involved in how services are planned, run and checked.



And make sure any changes to the way autism **assessments** are done are clearly explained to staff.



Local authorities and local health boards will write a report for Welsh Government every year about the area plan.



Welsh Government will check this to see if autism services follow the rules and laws.



Each area must have an autism champion. This person will go to **Regional Partnership Board** meetings and make sure autism services are properly checked.



They will also make sure autistic people and their family and carers have a say in autism services.

Duties for planning and checking services and involving people

Local health boards and local authorities must work together to:



- Select an **autism champion**. Make sure they are involved in the **Regional Partnership Board**.



- Follow their duties in the **Social Services and Well-being (Wales) Act**. And make sure they think about the needs of autistic people in their area plans.



- Make sure autistic people and their family and carers have a say in how autism services are planned and run.

Local health boards, NHS trusts and local authorities must:



- Make sure they follow Welsh Government rules for collecting information and checking services.

Hard words

Advocate

An advocate is someone who can help you speak up for yourself and make sure your views are heard.

Assessment

An assessment is a set of questions and tests that can be done to see if a person may be autistic, or to see if they need care and support.

Carer's assessment

A carer's assessment is when health and social care staff check what your carer's needs are and how they can support them.

Code of Practice

A Code of Practice gives rules and advice about the best ways of working. It explains how to follow laws and plans. We will call it the Code for short.

Diagnosis

A diagnosis is when health professionals look at a person's health and behaviour and decides if they have a condition or not.

Direct payment

A direct payment is money you can be given instead of a service. You can use it to buy your own support and services.

Eligibility

Eligibility is when there is a list of things you need to have to be able to get support. You are eligible for support if you have something on the list.

IQ

IQ is a score that says how intelligent or clever someone is.

Needs assessment

A needs assessment is when health and social care staff find out what your needs are and how they can support you.

NHS trusts

NHS trusts are organisations like the Welsh Ambulance Service and Public Health Wales.

Population needs assessment

The Social Services and Well-being (Wales) Act 2014 says local authorities and local health boards must work together to do a population needs assessment.

This is when they gather information to find out what the care and support needs are of the people living in their area.

Reasonable adjustments

Reasonable adjustments are changes we can make to make sure everyone is able to use services. For example giving extra time for appointments. Or giving information in easy read.

Regional Partnership Boards

Regional Partnership Boards are made up of staff from local authorities, local health boards, other partners and people. They work together to make sure health and social care services in their areas are planned well.

