How we deliver autism services in Wales

We want to know what you think

This is an easy read version of Welsh Government’s ‘Code of Practice on the Delivery of Autism Services’ – Consultation Document.

January 2019
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.

Some words may be hard to understand. They are in **bold blue writing**. They have been explained in a box below the word.

If the hard word is used again it is in **normal blue writing**. You can check what they mean in **Hard words** on page 34.

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This document was made into easy read by **Easy Read Wales** using **Photosymbols**.
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Introduction

We want to make autism services in Wales better. So we are writing this **Code of Practice** for how autism services should work.

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.

The aim of this **Code** is to help local authorities and health boards follow the **ASD Strategic Action Plan 2016**.

The **Code** will also help them to understand what different laws say they must do to help people with autism. 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
This **Code** will explain how local authorities and health boards **must** help people with autism in these 4 main ways:

1. **Assessments and diagnosis**

   An **assessment** is a way of finding out what care and support a person needs.

   A **diagnosis** is a way of finding out if a person has autism.

2. **Getting care and support**

3. **Raising awareness and training**

4. **Planning and checking services**
This Code will also say what local authorities, health boards and other service providers should do to make autism services the best they can be.

We want to know what you think about our ideas for the Code. And what you think should be in it.

Please read this document. Tell us what you think by filling out the easy read response form.

Please tell us what you think by 1 March 2019.
1. Assessment and diagnosis

Good assessment and diagnosis at the right time is very important.

Getting an assessment and diagnosis

In Wales we have special teams to assess and diagnose children and young people for autism.

We found out that autism diagnosis for adults was very poor. We have done a lot of work to change this. A big part of this is the Integrated Autism Service.

A main aim of this service is to provide a clear way to diagnose and assess adults for autism.

It is important that services for children and adults work in similar ways.
There should be clear information for everyone who needs services about:

- what services there are
- how you can get them.

Staff working in health, social care and education should know about autism services. And how people can get these services.

Everyone should start assessment and diagnosis in the same way. And you should not have to wait too long to be seen.

Services will be checked to make sure they do not take too long. And to make sure they are giving good services in the same way for everyone.
Children and young people

The NHS has written guidelines about how children and young people should be assessed for autism.

When a child or young person is sent for an assessment, the assessment team should be told:

- what signs and symptoms the child or young person has
- how those signs and symptoms affect them
- any risks to the child or young person.

The team will talk about this information.

They may decide they need more information before they can do an assessment. But they must do their best to do an assessment even if some information is missing.

If the team decides not to do an assessment they must explain why.
They should give advice about what more information they would need to do an assessment. Or what other services could give help. The child or young person and their family should be given this information.

Children and young people should get an assessment within 26 weeks of being referred.

If they need to be seen more quickly, the team should do what they can to make that happen.

Different types of health and social care staff should be part of the assessments. They should work together to write a profile of the child’s needs.

Children should be assessed for other physical or mental health needs at the same time.
Duties for assessment and diagnosis

Here is a list of the actions around assessment and diagnosis that local authorities and health boards must do.

Local authorities **must**:

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

Local health boards **must**:

- Give people assessment and diagnosis services.
- Make sure there is a clear way to get assessment and diagnosis. And follow national guidelines for the best ways of doing this.
- Put someone in charge of organising and checking how people get assessments and diagnosis.
• Make sure health staff like GPs know how to send people for assessment and diagnosis.

• Make sure people do not wait too long for their assessment.

• Send people diagnosed with autism to the National Integrated Autism Service for support assessments. People must agree to this first.

• Send people diagnosed with autism to social services for care and support assessments. People must agree to this first.

• Send people who do not get diagnosed with autism to social services if they need a care and support assessment. People must agree to this first.

• Make sure people with autism 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 they need to. And make sure staff working in these places understand when someone might have autism.

Local authorities and health boards **must** work together to:

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

Here is a list of actions that **should** be done to make services the best they can be. Local authorities and local health boards **should**:

• Work together and share information about the needs of children and adults with autism.

• 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.
2. Getting care and support

Autistic people are all different and have different support needs. Some can live independently. And some have other conditions that mean they need extra support.

The duties in this section of the Code explain how the Social Services and Well-being (Wales) Act applies to autistic people and their carers.

The Act tells local authorities how they must help people get social care services in 3 main ways:

- Information, advice and support.
- Assessment for care and support.
- Planning and giving care and support.

A main aim of the Social Services and Well-being (Wales) Act is to give people services that can stop problems happening or getting worse.
The Integrated Autism Service has been set up to make sure we can meet the needs of autistic people early on. And stop them needing more support in the future.

The Social Services and Well-being (Wales) Act says local authorities must:

- Check the needs of people living in their area.

- Look after the well-being of people and carers who need care and support.

- Give lots of services that can stop problems happening or getting worse.

- Give people information and advice about care and support. And help people get the care and support they need.
• Run an **Information, Advice and Assistance Service** to help people know what services are available. And make sure service staff have the skills to help autistic people.

• Have a clear process to **assess** and check support needs that is the same for everyone.

• Give an **assessment** to anyone who has care and support needs. People carrying out **assessments** must have the right skills and information.

The **Act** also says:

• What should be in care and support plans.

• When a person can use the law to make the local authority give care and support.
- What the **eligibility criteria** is for getting care and support.

**Eligibility criteria** is a list of things you must have or be before you can get care and support.

- When and how direct payments should be used.

**Eligibility**

The **eligibility criteria** for getting care and support looks at:

- A person’s situation.

- What a person wants and needs.

- What might be stopping them getting what they want and need.
• Any risks to the person or to other people.

• What the persons strengths and abilities are.

All these things must be thought about during an assessment and when planning support.

The result of an assessment will be 1 of the following:

• It is decided the person has no care and support needs.

• A specialist assessment is needed.

• The person needs information, advice or help to meet their needs.
• The person needs services to stop a problem happening. Or getting worse.

• The person can meet their own needs.

• The person needs a care and support plan.

Staff who do assessments must understand the needs of autistic people.

Any changes in the person’s life must be carefully planned. And local authorities must check assessments again to make sure they still work for the person.

Children and adults with autism can get social care services.
Young people who have autism and mental health problems will get support from Child and Adolescent Mental Health Services or CAMHS.

Children and young people should be seen by CAMHS within **28 days** of being referred.

4 in every 10 people with autism also have a learning disability.

Children with a learning disability and autism who have health care needs will get support from the team that did their **diagnosis**.

Some children who go to special schools get specialist support through their school.

Adults with autism and learning disabilities will usually get services from community learning disability teams if they have healthcare needs.
Duties for giving people care and support

Here is list of actions that local authorities and health boards must do when giving autism services.

Local authorities must:

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

- 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.

Local health boards must:

- Make sure health staff like GPs know about autism services in their area. And how people can get these services.
Local health boards and local authorities must work together to:

- Make sure there is someone in each Regional Partnership Board area to talk about the needs of autistic people.
- Work together to plan and pay for autism services.
- Make sure people have a say in how autism services are planned and run.
- Make sure there are clear ways for people with autism and mental health problems or learning disabilities to get services.
Here is a list of actions that should be done to make sure autism services are the best they can be. Local authorities and local health boards should:

- Help services to find new ways of working.

- Make sure people with autism and learning disabilities have extra support to get services if they need it.

- Make sure specialist services are available when needed.

Health Education and Improvement Wales should:

- Make sure they are involved in plans for staff in their local area.

- Make sure their health staff like GPs have autism training.
3. Raising awareness and training

The **ASD National Development Team** has done a lot of good work to raise awareness of autism.

More people in our communities know about autism. And many more professionals now understand how to meet the needs of autistic people.

There is lots of information and resources on the [ASDinfowales](https://www.asdinfowales.co.uk) website.

**Training for health and social care staff**

Lots of health and social care staff have now had autism training. This is thanks to the [ASD Strategy](https://www.asdinfowales.co.uk) and **ASD National Development Team**.

All staff who support autistic people should have the right skills and information.

The **ASD National team** has created lots of training resources for staff. It is available on the [ASDinfowales](https://www.asdinfowales.co.uk) website.
Local authorities, health boards and partners should make sure their staff have the right skills and information to support autistic people. They should check what training their staff need. They can use the **National Autism Training Framework** to help them with this.

Social Care Wales must make sure that social care workers have the right qualifications. They have made qualifications that include autism training.

We want to make sure autistic people and their parents and carers help make new autism training.

We have given money to start an **Adult Participation Network**. We are also working with the **National Parent Carer Forum**. This will help us get the views of parents, carers and autistic people.

Each **Regional Partnership Board** will also have an **ASD Champion**. This person will stand up for the needs of autistic people in their areas.
Duties for raising awareness and training

Here is a list of the actions that local authorities and health boards must do to raise awareness of autism and give autism training.

Local authorities must:

- Make sure everyone who does need assessments has the right skills and information. If they do not know about autism the local authority must make sure they get advice from someone who does.

- Make sure the **Information, Assistance and Advice Services** give information about autism services in their area.

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

Local health boards must:

- Make sure health care staff have the training and information they need to do their jobs.
• Make sure everyone doing **assessments** and **diagnosis** for autism 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.

Here is a list of actions that **should** be done to make sure autism services are the best they can be. Local authorities and local health boards **should**:

• Make sure autism awareness is part of equality and diversity training for all health and social care staff.

• Check how much autism training health and social care staff need for their different jobs.

• Make sure staff can get the right information, resources and training on autism if they need it.
• Make sure training follows the national guidelines. And make sure training 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.

Health Education and Improvement Wales should:

• Make sure they are involved in plans for staff in their local area.

• Make sure their health staff like GPs have autism training.
4. Planning and checking services

Local authorities and health boards must plan and run services that meet the needs of the people in their area.

They must work together to find out what the needs are of people in their area. And:

- How badly needs are not being met.
- What services are needed to meet the 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.

Regional Partnership Boards must make sure everyone can have a say when assessing needs of people in their area.
They will write a plan to say how they will meet those needs. And write reports to say how well they are doing on their plan.

**Regional Partnership Boards** bring together:

- Health
- Social services
- The third sector – charities and voluntary groups
- Local people
- Other partners.

**Regional Partnership Boards** are also in charge of the **Integrated Autism Service** in their area.

It can be difficult to get information about the needs of autistic people.

We usually only know about people who have asked for care and support. Many people may not have a diagnosis. Or may not want support.
The National Autistic Society says around 1 in every 100 people has autism. This number can be used to help plan services.

Any information we collect will be kept safe and private. We will follow the law on keeping and using people’s information.

Checking services

We use information about how many people have autism and how many get support to check services.

We also need information about how well services have helped people.

Services have worked together to create a way of checking how well services work for people.
Duties for planning and checking services

Here is a list of actions that local authorities and health boards must do when planning and checking services.

Local health boards must:

- Make sure they follow the rules about keeping information about how long people have to wait for autism assessments and diagnosis.

Local health boards and local authorities must work together to:

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

- Make sure autistic people, parents, carers and professionals have a say in how autism services are planned and run.
• Make sure there is a senior person who stands up for the needs of autistic people. This person will:

  ▪ Update the **Regional Partnership Board** about autism services.

  ▪ Check how local health boards and local authorities work together to plan and pay for autism services.

  ▪ Make sure everyone has a say in planning and running autism services.
**Hard words**

**Assessment**
An assessment is a way of finding out what care and support a person needs.

**Code of Practice** or **Code**
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 a way of finding out if a person has autism.

**Eligibility criteria**
Eligibility criteria is a list of things you must have or be before you can get care and support.