



Evaluation of the Autism Code of Practice

Phase 2:

- The progress made by people who work in autism services
- What autistic people, their families and carers think



How to use this document



This is an Easy Read version of: **Evaluation of the Code of Practice on the Delivery of Autism Services.**



Words in **bold blue** may be hard to understand. You can check what they mean on **page 40**.



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What this report is about



The **Code of Practice on the Delivery of Autism Services** is a set of rules that must be followed by law.



[You can read the Easy Read version of the Code here.](#)



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 this the **Code** for short.



The Code is a set of rules that must be followed by law. For example, the Code says:



- Councils and health boards must tell you about autism services in your area.



- They must help you get the support you need. And not keep you waiting too long.



- There must be information and training about autism that everyone can use.

This Code is for:



- Autistic people, their family and carers – so they know what services they should get.



- Autism service providers.



We are a charity group called **People and Work**.



The Welsh Government asked us to check autism services in Wales.



We looked at how well health boards and councils follow the **Code of Practice** for providing autism services.



We looked at this in 2 parts. In 2023 we wrote our first report, called Phase 1.



The report was about what people who work in autism services think about the Code.



[You can read that Easy Read report here.](#)



This is our second report, called Phase 2. This report is about:



- the progress made by people who work in autism services



- what autistic people, their families and carers think



- what we think should happen to make autism services better.

What we did



We helped services in each area to check how they were doing.



We talked to people in charge of making sure the Code is followed. This included people from health and social services.



We collected information in different ways:

- we talked with different teams
- did surveys with staff who are in charge in councils and health boards
- got views from autistic adults, parents, and carers
- we looked at websites, local plans, and other research and reviews.



We could not speak to every autistic person in Wales or their families, so some people may have different experiences.



The questions we asked autistic adults and parents and carers were different from the questions we asked staff.

What we learned

Diagnostic assessment



A **diagnostic assessment** is a set of questions and tests done to see if a person is autistic.



A **diagnosis** is when health professionals decide that a person has a condition.

There are 2 services in each area that support children and adults:



- **Children's Neurodevelopmental Services**



- **Adult Integrated Autism Services**

Children's Neurodevelopmental Services



The **Children's Neurodevelopmental Service** is a team of professionals.



They support children and young people who may have a **neurodevelopmental** condition. They also support their families.



Neurodevelopmental means the way your brain develops and works.

Neurodevelopmental conditions are things like Autism and ADHD.

Integrated Autism Services



There are 7 **Integrated Autism Services** in Wales. They provide:

- adult autism **diagnostic assessment**
- support and advice for autistic adults, parents and carers, and professionals.



The 2 services were doing most of the things in the Code.



But many areas still struggle to do **diagnostic assessments** for children within the time limit.



Some areas have fewer staff. This can make services hard to run.



Children's services cannot always give support before or after **diagnosis**.

Other services



Adult Mental Health Services and Learning Disability Services do not fully follow the Code.



People in some settings, like prisons, still find it hard to get **diagnostic assessments**.

What people said



Many people talked about support before or after **diagnosis**. Especially for children.



Parents and carers often expect that getting a **diagnosis** means they can get more help.



But after the **diagnosis**, they are often very upset. Because they do not get the help they want.

Getting information, advice and help



Getting information about autism services has got better.



Websites and local autism teams and groups have helped make information better and easier to find.



They help share information about autism services in their area.



Some people think that **Integrated Autism Services** are the only autism service in their area.

But there are many other services that:



- check adults for autism



- support autistic people, their families, and carers.



Some people said it can be hard to understand how all the different services work. And where to go for help.

Assessment services



Most local health board websites explain clearly how to find **Integrated Autism Services**.



Parents and carers say it is hard to access **Children's Neurodevelopmental Services**.



Information about **Adult Mental Health and Learning Disability Services** is not shared much.



People can get information on social care assessments through the **Information, Advice and Assistance service**.



The **Information, Advice and Assistance service** is part of your local council.



It provides information and advice. Or tells you where to go to get the information you need.



The law says every local council must have this service.

Rights and awareness



Not all autistic people know about their right to a **needs assessment**.



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



Not all carers know about their right to a **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.



There is not much information about these rights on websites.

What people said



Many people do not believe an assessment will help them.

This might be because:



- people do not always understand what an assessment means



- many people think an assessment is only useful if it shows they can get support.

Services for people with more than 1 condition



Councils and health boards have started giving support based on people's needs.



But they need a **diagnosis** to get support.



Autistic children and young people still find it hard to get support from mental health services.



The **Integrated Autism Service** can support autistic adults with more than 1 condition, unless they already get help from:

- Adult Mental Health Services
- Learning Disability Services



If services like the Integrated Autism Service and Adult Mental Health Services or Learning Disability Services work together, that can help people with more than 1 condition.

What people said



Most people said it was hard to get support from Mental Health or Learning Disability Services.



Many parents said Mental Health Services are only available when the problem gets worse.



Learning Disability Services mainly support people who struggle a lot with understanding and using information. Some people felt this left out others who also need support.

Raising awareness and training



Not all areas are following the Code in the same way.



Many staff do not know enough about Information, Advice and Assistance services.



Councils and health boards have done well in:

- training staff about autism. In some areas staff **must** do autism training
- giving extra training to staff who do assessments
- making sure that staff in autism services have the right skills and training.



Training

The **National Neurodivergence Team** has helped make useful training.



Some areas have also made their own autism training.



The Code has made managers take autism awareness training more seriously.

Training needs



Health and social care staff should have training that matches their job.



Many staff have done basic training. More advanced training is needed.

Involving autistic people



Autistic people, parents and carers should be involved in making and delivering autism training.

What people said



Many people said health staff, like GPs and nurses, do not know how autism affects their lives.



A few people said the same about social care staff.



Most people felt that health and social care staff would not make changes to meet their needs.



Like giving extra time for appointments. Or giving information in Easy Read.

Planning and checking services



There are autism groups in each area of Wales.



Some areas have an **autism champion**.



An **autism champion** helps people understand the problems that autistic people and their families face.



Autism groups across Wales work in different ways.



Some areas have bigger groups with more members.



This has helped to look at more types of autism services.



The rules in the Code have helped autism groups get more support from senior leaders. But it is too early to see the impact of these changes.

How the Code has changed things



More areas are following the Code since 2023.



The Code is helping:

- people get information and advice
- raise awareness and train staff about autism
- with planning services.



Local autism groups and regions are working to make services better. But there has been little change in getting assessments.



The Code only covers health and social care. It does not cover schools, jobs, or housing.

What makes it easy or hard to follow the Code

Some things that have made it easy:



- The Code is important and must be followed by law. It gives more power to people who want to change things.



- Other rules and laws that help with the Code, like: NEST/NYTH framework, Social Services and Wellbeing Act, Equality Act.



- Money from the Welsh Government to make national autism services.



- Help from the **National Neurodivergence Team**. This included a training plan, courses and information.

Some things that have made it hard:



- The Code is long, and not easy to use. This can make it hard for people to know if they are following the Code and what to do first.



- Health and social services are not always working together well.



- Health and social services have many people who need their help and not enough money. They have problems keeping and hiring staff.



- There are areas where no person or group has taken charge of checking how well they follow the Code.



- It can be hard to follow the rules because areas run services in different ways.



- Some funding is short-term or delayed.

How to improve services

What we think councils and health boards should do

Improve the planning and checking of services



Make local groups and autism champions stronger.



Listen to people's experiences and check services.



Include autistic people and carers in planning.



Make sure services make changes for autistic people. Like longer appointment times, or provide Easy Read information.



Check things like how **diagnostic assessments** work in learning disability and mental health services.



Use information and feedback to make services better.



Make sure funding supports new ideas and specialist services.



Include autism in policies and other areas of work.

Training



Include autism in staff training plans.

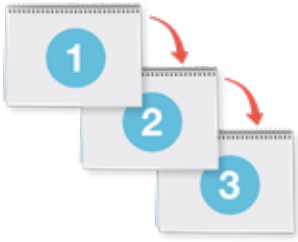


Make training **with** autistic people and carers.



Check if training improves staff skills and confidence.

Getting services



Make it clear how to get services.



Share this information with staff and the people.



Make sure people in prisons can get social care.

Diagnostic services



Provide support for people waiting for a **diagnosis**.



Make sure people in prisons can get **diagnostic assessments**.



Reduce waiting times for **diagnostic assessments**.



Use information from different reviews to make services better.

What we think the Welsh Government should do



Tell more people about the Code and what it means for them.



Make sure all services and teams work better together.



Use funding and support from the Welsh Government and its teams to make positive changes. For example:



- Share information and good ideas.



- Make guides and rules for staff working with autistic people.



- Make sure funding support local plans.



- Say what each team and autism champion should do. Show how these groups and people can work together to follow the Code.



- Look at how policies about things like autism can be included in other areas of work.



- Work with the **Neurodevelopmental** team and other groups that work on autism.



- Make the new Code simpler, clearer, and easy to follow. The new Code plans to include other conditions which often happen with autism, like ADHD.

Find out more



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This document is also available in Welsh.

Hard words

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Neurodevelopmental means the way your brain develops and works. Neurodevelopmental disorders are things like Autism and ADHD.