

Easy Read



Llywodraeth Cymru
Welsh Government

Evaluation of the Autism Code of Practice

Phase 1. What people who work in autism services think



This document is an easy read version of '[Evaluation of the Code of Practice on the Delivery of Autism Services](#)' written by People & Work.

December 2023

How to use this document



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Words in **bold blue writing** may be hard to understand. You can check what the words in blue mean on **page 39**.



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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 it 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 it the **Code** for short.



This **Code** is for:

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



The Welsh Government asked us to check how well councils and health boards follow the **Code**.



We will be looking at this in **2 parts**. This is the first part, called **Phase 1**.



This report includes:

- What people who work in autism services think about the **Code**.
- And what we think should happen to improve autism services.



The report shows:

- What health boards and local authorities do well
- What helps them
- What stops them from following the **Code**.

What we did



- We talked to people from the Welsh Government and the Welsh Local Government Association about the **Code**.



- We talked to people in each area of Wales who are in charge of making sure the **Code** is followed. This included people from health and social services, and autism leads.



- We made new ways to collect and check information.



- We looked at the websites of local councils and health boards to check how much they tell people about autism services.



- We told local autism groups and networks what we found out.

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.

The Code says:



- People should be able to get a **diagnostic assessment** for autism. And get help after. This includes people in prison.



- **Diagnostic assessment** services for autism must follow the best ways for working.



- Services should do **diagnostic assessments** for children within the time limit.

We found that:



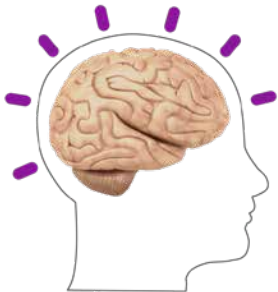
- Since 2015 the Welsh Government has spent a lot of money and worked to improve autism services for children and adults. They helped set up a:

- **Children’s Neurodevelopmental Service**

- and the **Integrated Autism Services (IAS)** in each area.



The **Children’s Neurodevelopment Service** is a team of professionals who support children and young people who may have a **neurodevelopmental** disorder, and their families.



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



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

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



- We found that these 2 services were doing most of the things the **Code** requires.



- Other services, like Adult Mental Health Services and Learning Disability, do **diagnostic assessments** for adults. We found that they were not always doing what the **Code** says.



- People sometimes did not know if Adult Mental Health Services and Learning Disability services follow the **Code**. People have not checked if these services follow the **Code** well.



- People sometimes did not know how people in prison could get a **diagnostic assessment**. Some people are confused about who should do this. People have not checked if these services follow the **Code** well.

We found that some people have problems getting an **assessment** and **diagnosis**:



- Lots of children and adults need a **diagnostic assessment**. This means that they must often wait a long time.



- It also means that services can have too much work to do. They do not have time to help people before and after a **diagnostic assessment**.

Getting information, advice and help

The **Code** says councils and health boards must:



- Tell you about the services for autistic people in your area.



- Help you find out how to get a **needs assessment** or 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.



- Tell autistic people that they can have a **needs assessment** and a **carer's assessment**.



- Not say no to you, if you need help while you are waiting for a **diagnostic assessment**.



- Not use your **IQ** score to decide if you need care or support.

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



- Health and social care services should share information.

Information about autism services



There is information about autism services in each area. But some people only know about **IAS**. The **IAS** is important, but it is not the only autism service that people need to know about.

Needs and carer assessments



Council websites say how to get a **needs assessment**. But it can be hard to find.



Services do not always tell people they can have a **needs assessment** or a **carer's assessment**. Some staff said they only tell people about **needs** and **carer assessments** when they think that person needs a lot of help.



- Some people think having one place for children to go for help is a good thing. This might mean they do not go direct to social services to get a **needs assessment**.



- Autism services and social care services often share information better for children than for adults.



- This is usually because the child and their family know social care services.



- Adults who get a **diagnostic assessment** from the **IAS**, are often not known by social care services.



- This can mean that information is not shared between health and social care services.

Services based on **diagnosis**



Councils and health boards should give you services based on what you need. And not if you have a **diagnosis** or what your **IQ** score is.



IQ should not stop you from getting help from services. But it can help to find the best service for you.



We found that some services need you to have a **diagnosis** before you can use them. For example, some **IAS** courses are only for people who have a **diagnosis**.

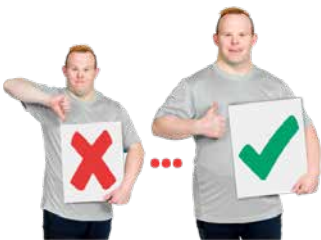
The **Code** has rules that say:



- If you are autistic and have other needs, like mental health or a learning disability, you can get the right help.



- If you are an autistic child or adult with mental health problems, you can use the mental health services.



We found that services for children with complex needs have got better.



We also found that services for adults with complex needs are not the same everywhere.

Raising awareness and training

The **Code** has rules to make sure:



- There is information and training about autism for everyone to use.



- People who work in health and social care can help you find information and support.



- People who work in health and social care are trained to do **diagnostic assessments** for autism or a **needs assessment**.

We found councils and health boards have done well in:



- Training staff in health and social care about autism.



- Training people who check what social care autistic people need.



- Making sure that staff in **Children's Neurodevelopmental Services** and the **IAS** know what they are doing.



- Some people said they did events to make people know more about autism. These were mainly for autistic people and their families.



Some places follow the rules better about training staff.

They have done well in:



- Giving general autism awareness training to health and social care staff.



- Giving more training to people who do **needs assessments**.



- Making sure that people in **Children's Neurodevelopmental services** and the **IAS** who do **assessments** for autism are good at it.



We found that The **National Neurodivergence Team** has helped by making training for everyone. Local autism leads have also done good things.



Some people said that the **Code** has made training more important.



The **Code** says that councils and health boards must work with autistic people and their families and carers to make and give autism training.



The **National Neurodivergence Team** has done this for their training so using their training is good.



Only a few places have worked with autistic people to make their own training.

What needs to be better:



The **Code** says that councils and health boards must check what autism training their staff need. And make sure they can get it.



Only 2 councils have checked what all their staff need. And made plans to train them. Other places are working on this.



Councils need to check what health and social care workers need to learn more about autism. And give them that training.



Some people who work for councils do not know about the **Information, Advice and Assistance Service**.



The **Information, Advice and Assistance Service (IAA)** is part of the Local Authority. It provides information and advice. Or tells you where to go to get the information you need.



The law says every local authority must have an **Information, Advice and Assistance Service**.

Planning and checking services

The **Code** has rules about:



- Making teams with autistic people and having a person who leads the work for autism in each area.



- Thinking about what autistic people need when they plan services in their area.



- Trying new things and having services that are good for autism.



- Checking how well the services are working.



The **Code** has helped people know more about autism groups.



The rules have helped some people to do their job better.

The teams that plan for autism services are different in each area. They all have a team, but:



- They have focused more on the **Children's Neurodevelopmental Service** and the **IAS** than other autism services.



- They do not always have people from the health board or council that can make decisions to improve services.



- It is not clear how the team that plan for autism services works with the **Regional Partnership Board that plans** services.



Regional Partnership Boards are staff from councils, local health boards, other partners and people. They work to make sure they plan the health and social care services in their areas well.



- They do not have people with autism or their families and carers in the team.



Some people said that the **Code** has helped them work better. And to get more managers involved.



It has helped some teams to have a clear goal of checking if they follow the **Code**.



But the **Code** has lots of rules. It can be hard for teams to decide what to do first because:



- There are so many things they need to do.



- They might only focus on the rules and not other things that matter.



- They might try to follow the rules without thinking why.

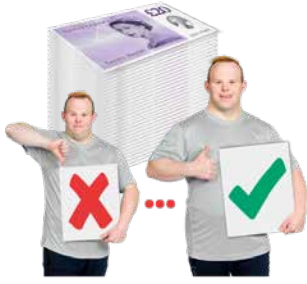


Some areas have had problems finding an **Autism Champion**. Some people who did it have left.

An **Autism Champion** helps people understand the problems that autistic people and their families face.



Many people do not know who their **Autism Champion** is in their area.



The Welsh Government has given more money to help with autism services. This has helped some places follow the **Code** more.



Some autism teams have not been part of deciding how to use the money. The money has also come late, so they cannot use it well.



The **Code** says that **Regional Partnership Boards** must collect information about autistic people and their services.



All places are doing this. But some places are not using the information to make better plans. Most places do not know much about how autistic people live and feel.



Population Needs Assessments include autism in each area. But most councils do not do this 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.



This means that the **Population Needs Assessments** are not helping to make better services for autism.



They need more information to make better **Population Needs Assessments**.

How the Code has changed things

Autism services have got better since 2015. For example:



- There are more **assessments** for autism. But there is a long waiting list.



- There is more help for people who are waiting for an **assessment**.



- There are services that give information and help to children, young people and their families. Like **IAA**, **Families First** and **Family Information Services**.



- The **IAS** helps autistic adults who do not get help from other services.

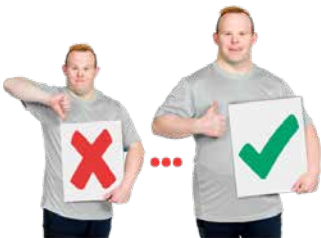
But in most areas the **Code** has not yet changed what people do. This means that it has not helped much with:



- Getting autism **diagnostic assessment** or a **needs assessment**.



- Finding information and advice.



- Making better services.



The **Code** only covers social and health services. It does not cover other things that matter, like school, work or housing.

What difference is the **Code** making?



The **Code** has made people look at the services they were ignoring. Like getting **diagnostic assessments** for autism in Adult Mental Health Services and Learning Disability services.



The **Code** has helped with training staff, but they need to do more work on this.

The **Code** has made councils and health boards look at things, like how:



- Adult Mental Health Services and Learning Disability services do **diagnostic assessments** for autism.



- People can find information about autism services.



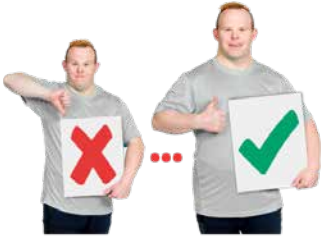
- To help autistic people in prison.



- To involve autistic people in making better training and services.

What we found out

Following the Code



We checked how well councils and health boards follow the **Code**. We found that they need to do better. They should:



- Make sure that **diagnostic assessment** done by Adult Mental Health Services and Learning Disability are done well.



- Reduce waiting times for children's **diagnostic assessment**.



- Make sure there are **reasonable adjustments** for autistic people.

Reasonable adjustments are changes so that everyone can use services. Things like giving extra time for appointments. Or giving information in easy read.



- Tell people that they can ask for a **needs assessment**.

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 has given more power to people who wanted to change things.



- Other rules and laws that help with the **Code**.



- Money from the Welsh Government to make national autism services like **Children's Neurodevelopmental Services** and the **IAS**.



- 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.

What we think councils and health boards should do



We have given advice to each council and health board to help them follow the **Code** better. The advice is about making changes in these areas:

Planning and making services:



Making the role of local groups and **autism champions** stronger.

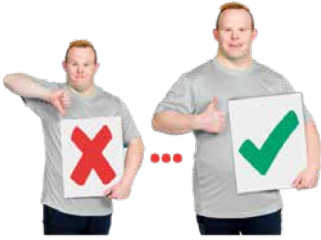


Working more with autistic people and their families.



Making planning tools better.

This will mean they can:



- Find out what works well and do more of it.



- Check what they are not doing well and work to fix it.



- Make sure they have a good plan for making autism services better.



Regional Partnership Boards and autism groups should decide what areas the autism group should work on. And what other groups should do.

The autism group should make sure they include autism in policies:



- Teaching people about autism. Making sure that councils and health boards find out what their staff need to learn. Work to make training plans and check how well they work.



- Telling people about services. Making it easier to find autism services in each area. Making sure:
 - Staff know about the **IAA** service and how to send people to this service.



- People who may need care and support know that they can ask for a **needs assessment**.



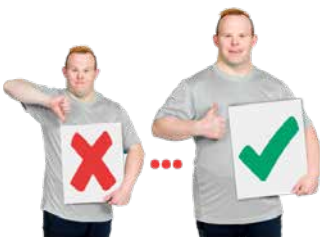
- Councils and health boards should use different ways to reach out to staff, autistic people and their parents or carers. Like websites, social media, Family Information Services, disability services.



- Make sure people have better access to **diagnostic assessments**.



- Health boards should work to get more **Neurodevelopmental** services for the people who need them.



- Improve how Adult Mental Health Services and Learning Disability services work.

What we think the Welsh Government should do



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



- Make the **Code** clearer on these topics:



- How to help people with autism in prison.



- What kind of **assessments** people with autism need and who should do them.



- Telling people with autism that they can ask for a **needs assessment**.



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



- Check if the local plans and reports cover autism well enough.



- Make sure councils and health boards use the money they give them to follow the **Code**.



- Think about making some guides and rules for mental health workers who work with people with autism.



In our **Phase 2** report we will look at what autistic people, their families and carers think.

Find out more

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This document is also available in Welsh.

Hard words

Autism Champion

An Autism Champion helps people understand the problems that autistic people and their families face.

Diagnostic assessment

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

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.

Children's Neurodevelopment Service

The Children's Neurodevelopment Service is a team of professionals who support children and young people who may have a neurodevelopmental disorder, and their families.

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 decide that a person has a condition.

Information, Advice and Assistance service - IAA

The Information, Advice and Assistance service (IAA) is part of the Local Authority. It provides information and advice. Or tells you where to go to get the information you need.

The law says every local authority must have an Information, Advice and Assistance service.

Integrated Autism Services - IAS

There are 7 Integrated Autism Services in Wales. The services provide:

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

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 care and support a person may need.

Neurodevelopmental

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

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 so that everyone can use services. Things like giving extra time for appointments. Or giving information in easy read.

Regional Partnership Boards

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