



Report on Neurodevelopmental Services

How to improve services for people with
Neurodevelopmental conditions



This document was organised and paid for by the **Welsh Government**. It was written by **People & Work**. This is an easy read version of 'Review of the Demand, Capacity and Design of Neurodevelopmental Services: Summary Report'.

January 2023

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 the words in blue mean on **page 32**.



Llywodraeth Cymru
Welsh Government

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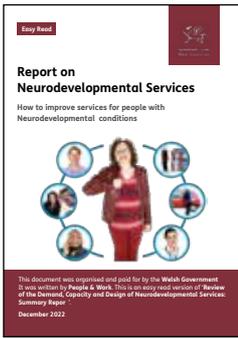
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Introduction



This is a report about **Neurodevelopmental** Services in Wales.

A **Neurodevelopmental** condition is when the brain has developed in a different way.

This can affect a person's behaviour, memory or ability to learn. It includes conditions like **ADHD** and **Autism**.



Neurodevelopmental Services in Wales offer **diagnostic assessments**.

A **diagnostic assessment** is when health professionals do a check of things like your health and behaviours to see if you have a **Neurodevelopmental** condition or not.

This is done through an **assessment** like tests, questions and looking through your history.

If you have a condition you are **diagnosed**.



They also offer support, information, and advice for people who may have **Neurodevelopmental** conditions.



We looked at **Neurodevelopmental** Services for children, young people and adults in Wales. We wanted to:

- find new ways to improve **Neurodevelopmental** Services
- and lower the pressure on these services.



We mainly looked at:

- **Children's Neurodevelopmental Services**
- **Adult ADHD Services**
- and the **Integrated Autism Service (IAS)** for adults.



And we focussed on **Autism** and **Attention Deficit Hyperactivity Disorder** or **ADHD**.

What we did



We looked at the plans, rules, and guides for **Neurodevelopmental** Services. And at the information given by **Neurodevelopmental** Services.



To write the report, we did interviews with:

- more than 70 people from different groups
- 7 parents and carers
- and 9 adults using the **Integrated Autism Service**.



And used questionnaires from:

- 14 adults
- 30 parents and carers
- 29 professionals



There were also 2 workshops to talk about what we found out.



We started a working group to talk about new ways to improve services and how this could be done.

What we learned

The need for diagnostic assessments



A lot of people want an **assessment**.



Neurodevelopmental Services are finding it hard to do enough **assessments**.



There are many children who need a **diagnostic assessment** for **autism** or **ADHD**, and the number is going up.



Many adults need an **assessment** for autism. The numbers have been high since the **Integrated Autism Service** started in 2017.



We do not know how many adults need a **diagnostic assessment** for **ADHD**. But mental health services say that the numbers are high.



There are a lot of people waiting for a **diagnostic assessment**.



To help them do more **diagnostic assessments**, **Neurodevelopmental** Services need:

- more admin support
- good IT equipment, like new computers
- more and better spaces to work in
- bigger staff teams with different job roles
- more money.





A lot of children must wait for a **diagnostic assessment** before they get the support they need.



People with **ADHD** are not **diagnosed** soon enough, if at all. Especially adults.



This is because people do not understand **ADHD** well.



Adults with **ADHD** depend on **mental health** services for **diagnostic assessment**.



Mental health is how someone is feeling in their mind.

Support



Many families said that they find it hard to get support.



Children's **Neurodevelopmental Services** often provide very little support.



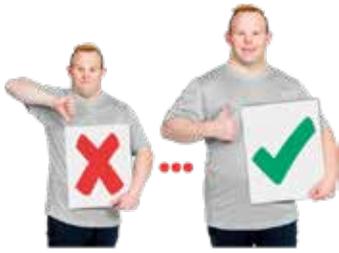
Families mainly depend on other services, like education and voluntary groups.



The **Integrated Autism Service** offers support to adults with Autism and parents and carers.



It offers support before and after **diagnosis**. Like helplines and drop-in sessions.



People need more and better support.

Some groups of people find it harder to get support.
For example:



- Adults with **ADHD** who need support with things like sleep and relationships.



- Children and adults who do not get a **diagnosis** when they are **assessed**.



- Children and adults who also have other conditions like **mental health** problems.

Other problems



People wait for a long time to get a **diagnostic assessment**. This means some people do not get the support they need in time. And there are chances of missing problems early on.



There is a risk of losing skilled and experienced staff in **Neurodevelopmental** Services.



Many people said it is hard to get support even after getting **diagnosed**.



It can be hard for services to reach people from Black, Asian and **minority ethnic** groups.

People from **minority ethnic** groups may have different beliefs, values, cultures, and skin colour compared to most other people in their community.

Cymraeg

Very few **Neurodevelopmental** Services offer their services in Welsh.

The way Neurodevelopmental Services are designed



Neurodevelopmental Services are not **person centred**.

Person centred means services identify the needs of a person, then works to meet those needs.



There is more focus on autism than ADHD. Especially for adults.



Transition between services can be hard.

Transition is a time of big change like moving from children services to adult services.

There are problems with **Children's Neurodevelopmental Services**. Like:



- They can find it difficult to work with hard cases. For example, a child that has more than 1 **Neurodevelopmental** condition or a **Neurodevelopmental** and **mental health** condition.



- Some have teams made up of people who come from different services. This can be harder to manage. Sometimes these teams do not work as well for people.



- They do not offer enough support before and after **diagnosis**.

There are problems with the **Integrated Autism Service**. Like:



- The service finds it hard to give long term support.
- They focus only on autism.
- The **diagnostic assessment** for **autism** and **ADHD** is done by different services.



Change will not be easy. It could take a lot of time and money.

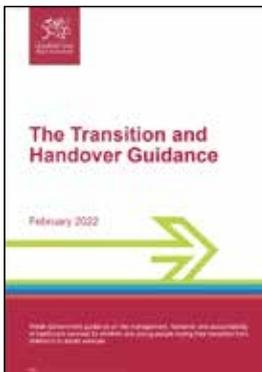


We must think about all the good and bad things before making any changes.



We will need good leaders at different levels. New ways of working and a better understanding of **Neurodevelopmental** conditions.

Improving transition between services



You can check the new Welsh Government guidance on **Transition and Handover** here: gov.wales/transition-and-handover-childrens-adult-health-services.

The guidance says we must:



- support **transition** to adult services where needed or find other services where this is not possible



- give information and support for young people and their families. Involve them in making decisions about **transition**



- follow a **person centred** way of working



- make sure that both child and adult services are friendly and welcoming



- check for feedback from people using the services.

Goals for Neurodevelopmental Services and the wider system



We set up a working group to find new ways to improve **Neurodevelopmental Services**.



The working group have set 3 main goals for **Neurodevelopmental Services**:

1. People should be able to get early help and support.
2. People should be able to get a **diagnostic assessment** quickly.
3. People should be treated fairly and equally.

3 beliefs to achieve these goals:



1. We should focus on early help and support. And work together with other sectors like health, education, social care, and voluntary groups.



2. We should follow a more **person centred** way of working.



3. We should focus more on what is important to people using services. And work together with partner organisations by sharing feedback from people.

Ideas to make things better

Early help and support



Getting early help and support without needing a **diagnosis** could help services.

To make this happen, we will need to:



- Raise awareness about **Neurodevelopmental** conditions.



- Have training for staff in places like schools, primary health services and voluntary groups.



- Make sure everyone is included. Reach out to children and adults from Black, Asian and **minority ethnic** groups.



- Make sure services are offered in Welsh.



- People get the right information and support from places like GPs, social services, and Information Advice services.



- Make sure support is offered in the same ways across Wales. To make this happen we will need to write plans and guides, have staff and funding.



- Different services should work together to make sure **transition** is better.



- The Welsh Government should find out why people with **Neurodevelopmental** conditions find it hard to get help for **mental health** problems.

Goals

Develop Children's Neurodevelopmental Services and improve transitions

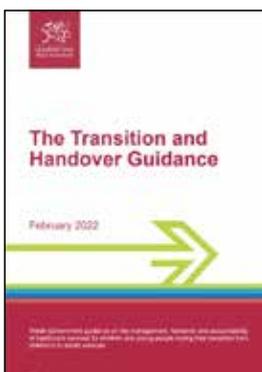
Short term goals:



- More funding to improve services through things like admin support, IT equipment and better spaces.



- Every **Neurodevelopmental** Service should write a plan for Welsh Government and Local Health Boards, It should have ideas to improve services and how much money they would need to do it.



- Follow the new Welsh Government guidance on **Transition and Handover:** gov.wales/transition-and-handover-childrens-adult-health-services.

Long term goals:



- Have the right staff with the right skills. Have more staff in different roles like therapists and specialist nurse practitioners.



- Collect information to understand the challenges services face. Also, check on things like people's experiences of the services.



- Make the service bigger with more staff. Create new job roles to give advice, support, and training.



This would also help to provide better support before and after **diagnosis**. For example, specialist nurses who could help to give support in schools and at home.



- It is important to check what is working well and what needs to change to improve services.



- The Welsh Government and **Local Health Boards** should think about how **Children's Neurodevelopmental Services** can support other **Neurodevelopmental** conditions.



- If we cannot improve **transition**, we must think of other ways to make things better.



For example, by having a national working group to find out if we could have a **Neurodevelopmental** Service for all ages.



- If we cannot make services more **person centred**, we must think of other ways to make things better.

Develop the Integrated Autism Service

Short term goals:



- More funding to improve services through things like admin support, IT equipment and better spaces.



- Every **Integrated Autism Service** should write a plan to the **Welsh Government, Local Health Boards, Regional Partnership Boards** and **National Autism Team**. It should say how much money they would need to improve services.

Long term goals:



- Have the right staff with the right skills. Have more staff in different roles like **assistant psychologists** and **specialist nurse practitioners**.



- The **Welsh Government** or **National Autism Team** should find out why support provided by every **Integrated Autism Service** is different.



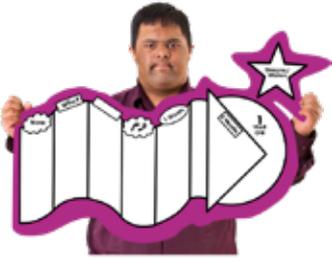
- The **Integrated Autism Service** and **ADHD Services** should work together when needed. For example, when an adult might have both **autism** and **ADHD**.



- If we cannot improve **diagnostic assessment** and support for adults with more than 1 **Neurodevelopmental** condition we must think of other ways to make things better.

Provide better services for adults with ADHD and the parents and carers of children with ADHD

Short term goals:



- Have a clear way for getting a **diagnostic assessment** for **ADHD**. All sectors, like health and education should know how to refer people for an **ADHD assessment**.



- Make sure people with **ADHD** can get help and support for **mental health** problems.

Long term goals:



- Have more staff. With more staff, the service should be able to offer support to parents and carers of children with **ADHD**. For example, in schools and through voluntary groups.



- Local health boards should start new services like adult **ADHD** services. So more people will be able to get a **diagnostic assessment**.



- Make sure adults with **ADHD** can get support. **Local Health Boards** or **Regional Partnership Boards** should look into getting support workers for adult **ADHD** service.



Or the **Integrated Autism Service** support workers will have to be trained to also support adults with **ADHD**.



If services working together does not improve people's experiences, we must think of other ways to make things better.

Provide assessment and support for people with more than 1 Neurodevelopmental conditions

Short term goals:



- The Welsh Government should find out why people with **Neurodevelopmental** conditions, who also have **mental health** problems find it hard to get help from **mental health** services.

Long term goals



- Have experienced health professionals and teams who can assess more than 1 **Neurodevelopmental** condition.



- **Local Health Boards** should make sure **Children's Neurodevelopmental Services**, the **Integrated Autism Service** and **Mental Health Services** work together.



- The Welsh Government and Local Health Boards should check what services and support are available for:

- people **diagnosed** with other **Neurodevelopmental** conditions

- and for people who are not **diagnosed** with any **Neurodevelopmental** conditions.



If services working together to support people with more than 1 **Neurodevelopmental** condition does not work, we must look at other ways to make things work.

Hard words

Diagnostic Assessment

A diagnostic assessment is when health professionals do a check of things like your health and behaviours to see if you have a Neurodevelopmental condition or not.

This is done through an assessment like tests, questions and looking through your history.

If you have a condition you are diagnosed.

Mental health

Mental health is how someone is feeling in their mind.

Minority ethnic

People minority ethnic groups may come from different countries. They may have different beliefs, values, cultures and skin colour compared to most other people in their community.

Neurodevelopmental

A Neurodevelopmental condition is when the brain has developed in a different way.

This can affect a person's behaviour, memory or ability to learn. It includes conditions like ADHD and Autism.

Person centred

Person centred means services identify the needs of a person, then works to meet those needs.

Transition

Transition is a time of big change like moving from children services to adult services.