

A New Path Ahead (Easy Read)

Why changing public services can help autistic people have better lives

About this report

This report has been written to help an independent review which is happening in England. The review is about mental health, ADHD and autism.

It is also to help the Government decide plans for the next National Autism Strategy for England.

It can help governments in Scotland, Northern Ireland, and Wales too.

Different people helped to write this document, including:

- Autistic people (young people and adults).
- Parents and carers of autistic young people and adults.
- Researchers and clinicians.
- Charities.

Summary of this report

This report has one main message.

To make things better for autistic people, governments need to assess their strengths and support needs **and** change the way public services work

If governments don't change services, needs assessment could be used to block diagnosis and support. This could cause more harm.

What the report says

Autistic children, young people and adults are part of our communities.

They have strengths and they may need support. They may also need public services to make adjustments. This can include education, health, social care, housing, jobs and the justice system.

With support and adjustments, autistic people can have a good quality of life and take part in work, education and their community.

Supporting autistic people can also save money in the long term, because it can prevent crisis and reduce extra costs later on.

But many services do not make the adjustments autistic people need, and many autistic people don't get support.

Because of this, autistic people can face serious harm, such as:

- mental health crisis
- self-harm
- suicide
- poor physical health and early death
- being left out of school, work or their community
- very low employment rates.

An autism diagnosis can help people understand themselves. It can also help families understand and support each other.

For some people, a diagnosis also helps them get the right health support and social care.

Getting support should not depend on having a diagnosis, but many services only offer help if people have a diagnosis.

As well as this, autism assessment waiting lists are very long.

This means people can be blocked twice: they wait a long time for diagnosis, **and** they cannot get support while they wait.

As well as issues with diagnosis there are some big problems that make it hard for autistic people to live a good quality life.

- Too many people in society still have attitudes about autism which aren't based on facts.
- Many staff in public services do not understand autism well.
- It is not always clear who is responsible for making sure autistic people get good outcomes.

There is an opportunity to change this. It is called a strengths and support needs assessment, and would look at:

- what a person is good at (their strengths)
- what support they need day to day (their support needs)
- what changes services should make.

All public services could use this assessment to make adjustments for autistic people.

People who commission services could use the assessment to fund the right support.

An assessment could help public services work together so that support is available when it is needed.

It could also help people get support while they are waiting for a clinical autism assessment.

But if this strengths and support needs assessment happens **without changing the way services work**, things could get worse.

This is because:

- Services have too much pressure on their staff and money.
- And some people are saying there are 'too many autism diagnoses'. They want to see fewer autism diagnoses despite diagnosis being positive for autistic people when it is provided with support

Because of these problems, strengths and support needs assessments could be used to block access to support and block access to diagnosis.

This would increase harm for autistic people.

It could also increase costs later, for example in mental health services and the justice system.

To avoid this happening, services must change and support must improve **before** strengths and support needs assessment is used everywhere in the country.

This will require government investment and a big push to change services. It will take several years.

If governments get this right, autistic people and families can have better lives. Changing public services can also save money by preventing crisis and helping people earlier.

There are four recommendations. The recommendations are for all the governments of the UK, in England, Scotland, Northern Ireland, and Wales.

1. Reduce waiting times for clinical autism assessments.

Governments should increase the number of staff who make clinical assessment and improve how clinical assessment services work, so people can get diagnosed sooner. Clinical assessment should also reflect all types of neurodivergence and mental health needs.

2. Put better support in place across health and social care.

People should get the right level of support at the right time, so needs do not grow into crisis.

3. Tackle stigma and improve understanding and responsibility.

Services should train staff, make reasonable adjustments, and be clear about who is responsible for outcomes for autistic people.

4. Design and test a standard way to assess strengths and support needs.

This should be co-designed with autistic people and families. It should start with people waiting for diagnosis and then be used for more people. It should not be used everywhere and for everyone until services are meeting needs and outcomes are improving.

Governments in England, Scotland, Northern Ireland, and Wales should work with autistic people, families, charities, researchers and the NHS to plan and deliver these changes. People involved in this report want to help.

Words we use

- Clinical autism assessment: meetings and checks to see if clinical professionals agree a person is autistic.
- Diagnosis: when a clinician confirms someone is autistic.
- Adjustments: changes services should make to reduce the distress autistic people can experience.
- Support needs: the help someone needs to live well (for example with communication, daily living, school, work or mental health).
- Strengths and support needs assessment: a way of finding out about an autistic person so the right support and adjustments can happen. It is not clinical like a diagnosis.
- Stepped support: different levels of help, with the option to increase help quickly when needs increase.