



# Progressing Autism Assessments for Adults

March 2022

**healthwatch**  
West Sussex

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# Introduction

# Introduction



In July 2021, we published our [report](#) demonstrating the impact adults experience when waiting a long time for an autism assessment/diagnosis.

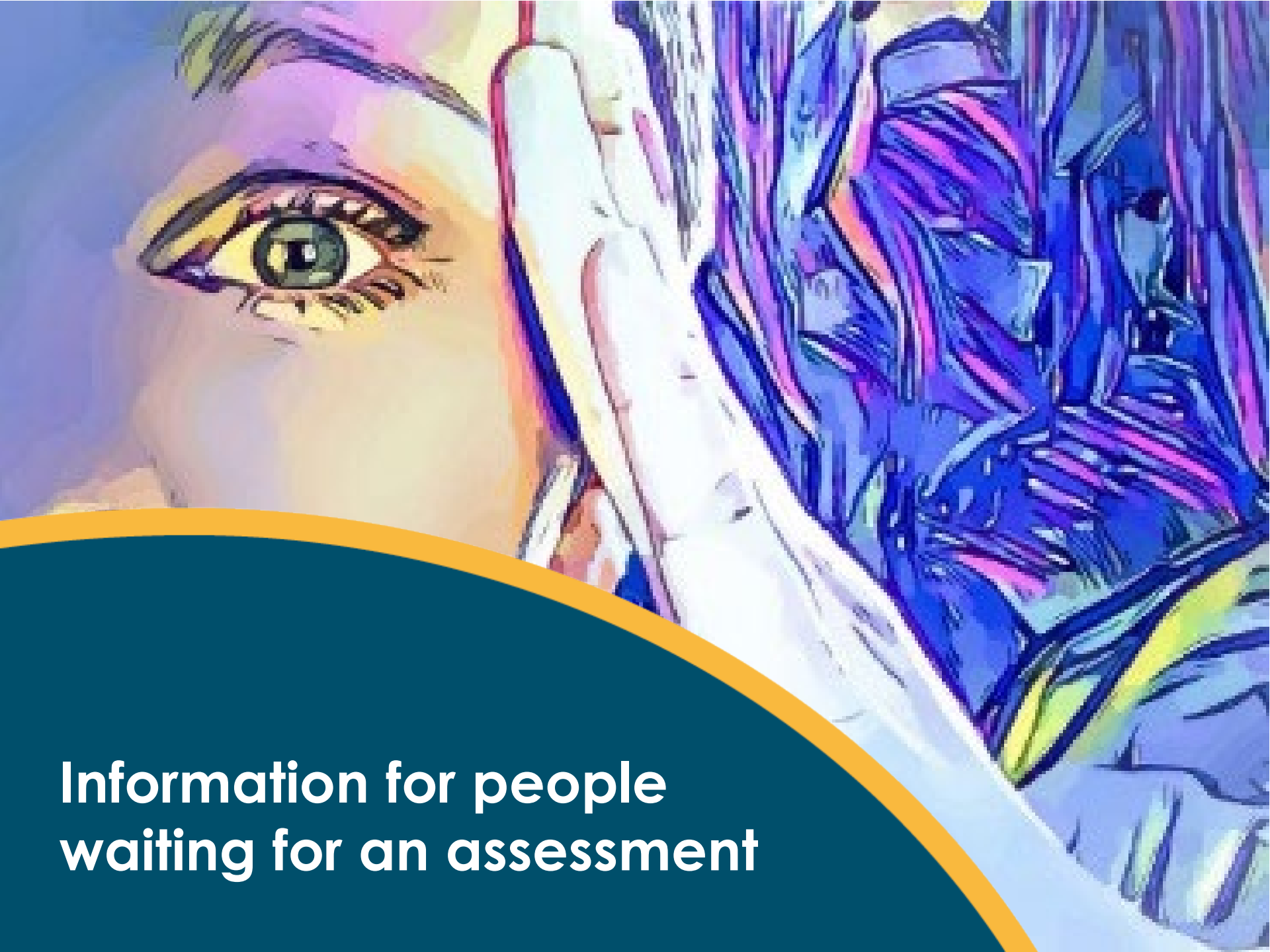
In this report, we made 10 recommendations and called for urgent action to improve the lives of those waiting for a neurological assessment. This assessment is often vital in someone understanding their neurodiversity and also the key to getting much needed support.

On 22 July 2021, the Government published a national strategy for [Autistic Children, Young People and Adults for 2021 to 2026](#), which should help drive forward progress.

We're delighted that in West Sussex, commissioners are paying for additional resources by out-sourcing over 500 assessments. This means children and young people waiting for a neurological assessment should get a diagnosis and support sooner. This may also ease the demand for adult services.

However, the service has told us that since we reported last year, the demand for an adult neurodevelopmental assessment has increased (up by 2% month on month.)

**We're publishing this report to give people an update from Sussex NHS Commissioners and the Neurodevelopmental Service on what has happened in the last nine months.**



**Information for people  
waiting for an assessment**

# What may be helpful to know if you are waiting for an assessment

Sussex Partnership NHS Foundation Trust is looking at the possibility of out-sourcing assessments to private businesses to reduce the waiting list. The Neurodevelopmental Service, including neurodiverse team members, have been involved in the process and have rejected organisations they don't feel are appropriate.

The Neurodevelopmental Service has a steady and happy workforce despite the pressures on the service. The team employs a high number of neurodiverse people. This means staff understand some of the challenges you may face.

The staff are committed to supporting people and are developing peer support in several ways. The Trust has a staff forum and clinics that support staff with ADHD and autism and this in turn helps the staff support other people.

An improvement roadmap is being developed and should be in place by April 2022. We're asked for this to be made public so people can understand what is being planned.

The service is finalising a briefing for local politicians, so they are aware of what is being done. We've asked for this to be shared further, including with the community and voluntary groups supporting neurodiverse people.



**What has changed  
strategically?**

# What commissioners shared

## A strategic overview



Receiving a timely autism diagnosis is vital in getting the right support and helping autistic people and those supporting them to better understand their needs.

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A specialist was commissioned to look at best practice and to map this against what was happening locally. This work included nine workshops across Sussex (covering all ages).

A paper went to the Sussex Executive Management Team in November (2021), which detailed the gaps and priorities for improvement. We are told that these decision-makers supported the findings. It should be noted:

- £7+million extra funding is requirement over the next three years.
- COVID (Omicron) delayed progress, but this work is now being picked up and a programme director has started.
- There is still a need to understand all the bits of the jigsaw to clarify what the programme director will lead on and what else needs to be looked at.
- Regional work is happening that supports the ambition to improve the outcomes for autistic people. Sussex Health and Care Partnership (our integrated care system partners) are taking part in this work.





**What has changed within  
the Neurodevelopmental  
Service?**

# What the Service shared

The national but conservative estimate is that 1% of the UK population is autistic. The service currently knows about half of the Sussex population in this estimate.

The team has worked to understand the demand and capacity requirements of the service. They need to understand how much it will take to stabilise the waiting list and how much to start to reduce it. This is important:

- So that they know how quickly the service can respond if more funding is made available, recognising that recruitment is a challenge.
- So that there is a realistic expectation about what can and cannot be delivered when funding is made available.

## **The changes that have happened so far:**

- The Trust/Service has invested in new staff to make the current situation safer. They have increased their triaging capacity with extra staff to prioritise referrals and people waiting for an assessment.

SPFT (Sussex Partnership NHS Foundation Trust) will continue to work with commissioners to ensure that the funding for the service is sufficient on a sustainable basis.

- Letters are being sent to people waiting for an assessment to let them know that waiting estimates may have changed. The service has received positive feedback to this communication.
- These letters have been co-produced with autistic people. The letters let people know that their referral acceptance can be used to show that they're on the Autism Assessment Pathway. This may help to remove some of the barriers to accessing support/benefits.
- They are also making a video to give people more information.
- The healthcare professionals who make referrals have been sent clarification about what the service needs to know.
- The service is developing a workforce strategy for staff development, for example, the duty triage workers will be trained to be specialist practitioners.
- The Trust has the ambition to have an academy to train the workforce and to provide in-house and external training.



**Next steps**



## Next steps

We'll continue to push for **the improvement roadmap to be published** and will include details in our monthly Heads Up newsletter. To sign up visit our [Home Webpage](#) and fill in your details at the bottom of the page.

We'll be sharing this report with the West Sussex Autism Partnership for comment.

We're keen to get **feedback from people who have recently received a letter** from the Neurodevelopmental Service or if you have outstanding questions. We'd particularly like to understand how well the letter helps people to access support.

Please share your feedback with [caroline.whiteman@healthwatchwestsussex.co.uk](mailto:caroline.whiteman@healthwatchwestsussex.co.uk)

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