



University of  
Nottingham

UK | CHINA | MALAYSIA



NOTTS PSYCH POD

Policy brief: June 2024

# Access to care for neurodiversity: ADHD and Tourette Syndrome

## The importance of support for neurodiversity



## Summary

Around 15-20% of the population is neurodivergent. Despite this, access to diagnoses and care for neurodivergent people is problematic and there is inconsistent support across the UK.

Research at the University of Nottingham focuses on the importance of being diagnosed with neurodivergent conditions, such as attention deficit hyperactivity disorder (ADHD) and Tourette Syndrome, and having access to appropriate care and support.

We have developed a free, online ADHD training program with and for healthcare professionals. This is also being developed for tics and Tourette Syndrome.

We have shown that this training successfully increases GPs' knowledge of ADHD, which leads to reduced stigma and improved care. Appropriate awareness and support for neurodiversity results in individual, economical and societal benefits.

**Dr Blandine French** ([blandine.french@nottingham.ac.uk](mailto:blandine.french@nottingham.ac.uk)) and  
**Dr Maddie Groom** ([maddie.groom@nottingham.ac.uk](mailto:maddie.groom@nottingham.ac.uk))

**Notts Psych Pod team:** Rachel Grasmeyer Allen, Dr Daniel Jolley, Dr Lauren Marsh and Prof Nicola Pitchford.

Scan to  
listen to  
our  
podcast!



# The Problem

Despite their prevalence, there is **a lack of knowledge of, and support for, neurodivergent conditions** like ADHD and Tourette Syndrome. Our research has shown that **people often struggle to get a diagnosis** of these conditions, and without a diagnosis **they cannot access appropriate care and support.**

The care pathway for neurodivergent conditions typically involves General Practitioners (GPs) referring people for a diagnosis and support. It is therefore **essential that GPs have an understanding** of these conditions and their associated care pathways, but this is **not always the case.**

## Recommendations

- Neurodiversity awareness is needed across UK healthcare. **Training should be compulsory for all healthcare professionals**, especially GPs. **This will improve access to diagnosis and care pathways.**
- Services need to be reorganised to **provide better multidisciplinary care.**
- **Changes need to be adopted regionally and nationally**, and there should be fully funded, commissioned care pathways throughout the UK.

## Our Research

We conducted interviews and surveys with healthcare professionals. When producing the ADHD GP training, we had multiple stages of feedback to ensure the training was tailored to their needs. We evaluated the success of this training with surveys and follow-up interviews. We have also run focus group for people with Tourette Syndrome and their families to learn their experiences of diagnoses and care pathways.

## Quote

**'It is Kafkaesque trying to get a diagnosis and then there's a whole hidden queue inside the tent to get treatment'**

**- Neurodivergent person**

# Our Findings

We have shown that it is not compulsory as a healthcare professional to know about neurodivergent conditions. As such, there is a **lack of awareness**.

GPs and other healthcare professionals have a key role in diagnosis and care pathways. This lack of knowledge leads to **difficulties in getting diagnosed**. This, in turn, leads to **difficulties accessing care**.

Our GP training was successful in **improving GPs knowledge**. This short, free intervention can have real impact.

- **98% of GPs** reported **better knowledge, reduced misconceptions and improved attitudes and confidence** towards supporting people with ADHD.
- **92% of GPs** said it would **positively impact their practice**.
- The training has been **accredited** by the Royal College of General Practitioners and **translated to three different languages**.

Our research has also shown a clear **lack of specialist knowledge of, and support** for, Tourette Syndrome.

To address this, we are developing another GP training for Tourette Syndrome.

# Implications

Our online training **should be completed by all healthcare professionals** to allow diagnoses to be made as early as possible, so support can be accessed as soon as possible.

Increasing awareness of neurodiversity will improve the well being of individuals and will have positive consequences for society, both socially and economically.

## Call to Action

"Invest in services to meet [the] rise and recognition of [neurodivergent] needs and invest in [neurodivergent] populations to support them to self care while they wait for this professional help."

- Neurodivergent person

## References

ADHD training: [www.adhdinfo.org.uk](http://www.adhdinfo.org.uk)

<https://tinyurl.com/TourettesHearUs>

<https://ndlab.org.uk/> (please see publications under "GP ADHD Training")

ImproviNg Tic Services in EnglaND (INTEND) study

Tic Disorders and Tourette Syndrome: Exploring the INTEND Project

Marino et al., (2023), BMC Health Services Research