

# **Neurodiversity Programme All-age Autism and ADHD Deep Dive report**

Mapping existing Autism and ADHD provision, analysis of existing pathways, services, governance, costs in each place.

#### Introduction

West Yorkshire Health and Care Partnership aims to achieve a 10% reduction in the gap in life expectancy between people with mental ill-health, learning disabilities and autism/neurodiversity, and the general population. We are all different, we think differently, process and communicate differently, have different cultural norms and those differences make our society. Achieving this ambition will make life better for more than 200 000 people living in West Yorkshire.

This video has been made by a group of young people who have helped us with our work and explains what life can be like for neurodivergent people.

A key part of our work in 2022-2024 is an all-age Autism and ADHD deep dive. While the national focus is on Autism, our Partnership also wants to raise the profile of ADHD and will be using our collective voice to lobby for more support for this agenda. We also recognise wider neurodivergence and co-existing conditions, including, for example, Dyspraxia. We are using the insights gained from our Deep Dive to guide our future work.

# We have been working with people who use, fund and deliver services across West Yorkshire in order to:

 understand the current experience of users and families of autism and ADHD services, map existing autism provision, analyse existing pathways, services, governance and costs in each of the five places in West Yorkshire (Bradford District and Craven, Wakefield, Leeds, Calderdale and Kirklees)

- assess place and system-wide initiatives and ways
  of working in each place and across the whole
  West Yorkshire system to see if these are, or could
  be, improving how the system works and what is
  the impact on individuals and families
- explore options to proactively address future projected need/areas of work and support the development of sustainable services.

Our ambition is to make the best use of our collective expertise, including lived experience, to improve services, influence the wider determinants of health and in particular address social inequalities faced by neurodivergent people or those seeking a diagnosis of autism and/or ADHD (for the purpose of this work the term neurodivergent will primarily focus on autism and ADHD).



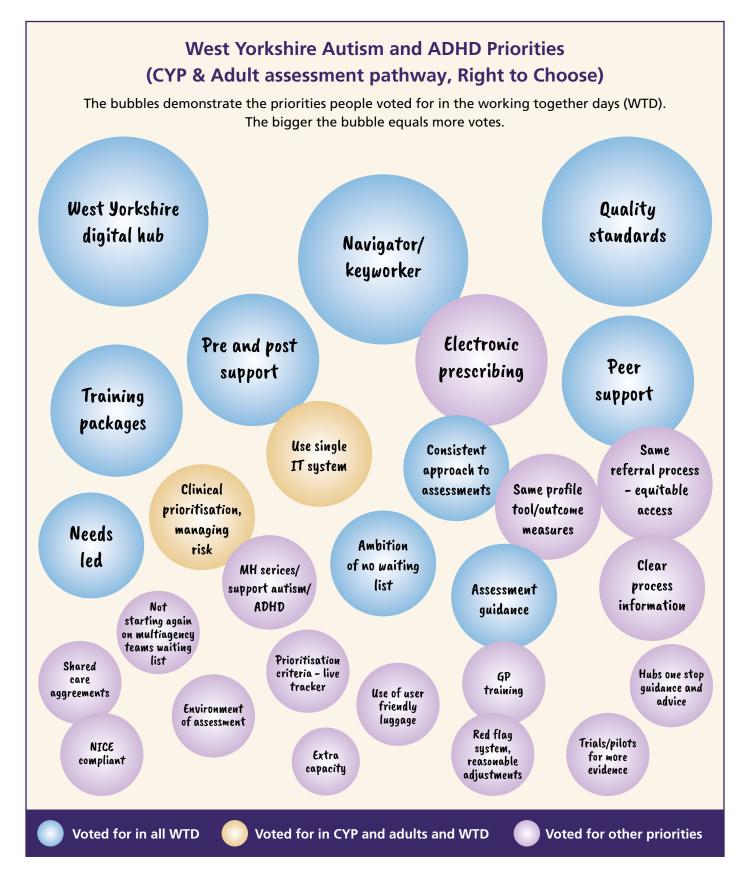
### What we did - co-production

One of our key principles is to work across sectors and with people with lived experience. In order to work collaboratively we aim to involve:

- people who use services
- people who fund services
- people who provide/deliver services.

We worked with more than 200 people to hear their experiences, with the aim of using their views to form the basis of our project.

Over three working together days we focused on the Children and Young People (CYP) neurodevelopmental assessment pathway; the Adult neurodevelopmental assessment pathway, and the Right to Choose agenda. The image below shows the priorities that the people who took part set for us.



Co-production has been an integral element of this project, working with people who use services and their families/supporters to understand their experiences and explore opportunities. During August and September 2022, we held six virtual participation sessions to hear people's experiences of their assessment journey. We held two sessions for young people, two for adults and two for parent/ carers, to read further details.

Individual interviews also took place in an accessible way for people and here are some <u>case studies that</u> <u>emerged from those interviews.</u>

We continue to work with our adult co-production group and young person co-production group, and now have two young people ambassadors and an adult ambassador representing the voice of people with lived experience to shape and influence the work.

Co-production Thrive by Design report

### Why we need to do this work

Society's awareness of autism has increased with an estimated 99.5% of the public having heard of autism according to the National Autistic Society (The Autism Act, Ten Years On). Nationally, there has been an unprecedented increase in demand for autism and ADHD assessments, and NHS data shows that between April 2021 and March 2022, the number of patients with an open referral for 'suspected autism' has increased from just over 74,000 to just over 103,000 across England - a 40% increase. The data also shows the majority (800,000) are waiting longer than three months to be seen following a referral.

In West Yorkshire 12,741 Autism and ADHD referrals were accepted in the year 2021 - 2022 for adults and CYP. The same six-month period in 2020/2021 - 2021/2022 shows an increase in referrals accepted of 83% (not including 'Right To Choose' assessments with external providers) with 8139 CYP referrals accepted, and 4602 Adult referrals accepted. The demand has continued to increase with 140,000 people nationally waiting for an autism assessment in December 2022.

As a system we need to be able to adapt and respond to these demands and work together to meet the needs of people regardless of diagnosis by improving knowledge, training and skills among our workforce. We also want to use research and expertise in areas where there are higher numbers of people with neurodevelopmental conditions such as eating disorders, mental health admissions for children and young people, risk of suicide and mental health admissions for children and young people.

Ultimately we want all sectors across our Partnership to work together to achieve better outcomes for our neurodivergent population.

# Using information to make things better for people

The first six months of the deep dive work focused on people's experiences of the neurodevelopmental assessment journey. We collected information from assessment services across West Yorkshire, and found that there are differences across our five places which can make it difficult to analyse what is working and what is not working. It is clear that to create fair services we must agree a consistent approach across and collect information in such a way that helps to benchmark, monitor and address inequalities.

### As a result of this work, we have identified West Yorkshire ambitions:

- to have appropriately resourced neurodevelopmental services, providing value and sustainability
- to have a consistent approach across West Yorkshire to ensure equitable access and address inequalities

### What's next?

We know that there is much to do across our partnership to improve the lives of people living in West Yorkshire and as can be seen from the illustration, we have had lots of engagement, learning and ideas shared with us. Our objectives for the next year are a result of listening to what people told us were their priorities and what we are able to deliver with our current capacity. We will continue to work together to address inequalities and barriers, share learning and good practice and take advantage of new opportunities.

### Objectives to work on together during 2023/2024:

- to improve consistency in Autism and ADHD services, reduce wait time and barriers to access
- to improve the availability of person centred, needs led, holistic support
- to implement the 'Right To Choose' agenda consistently across West Yorkshire

• to continue to embed co-production in the neurodiversity review, working with people with lived experience and professionals to create shared perspectives and learning to shape services.

These objectives will be achieved through our forums and working groups for CYP and Adults. Having an all-age project plan helps us to consider

transition age, SEND requirements and have a better understanding of risks and impacts, whilst at times there may need to be a separate focus on children, young people and adults. It has also been recognised within children's services that an understanding of the different developmental needs and services for under five years are essential. Each of our five places

will continue to focus on Autism and ADHD and we will work and support across West Yorkshire where we can

## **Neurodiversity**



