

The autism diagnostic pathway for adults

Derby City Council Adults and Health Scrutiny Review Board



What is autism?



Autism affects the way a person communicates and how they experience the world around them. It is considered a spectrum condition. While autistic people share some similar characteristics, they are also all different from each other. The autism spectrum isn't linear from high to low but varies, just as one person might vary from another.



Autism is a spectrum condition and affects people in different ways. Like all people, autistic people have their own strengths and weaknesses.

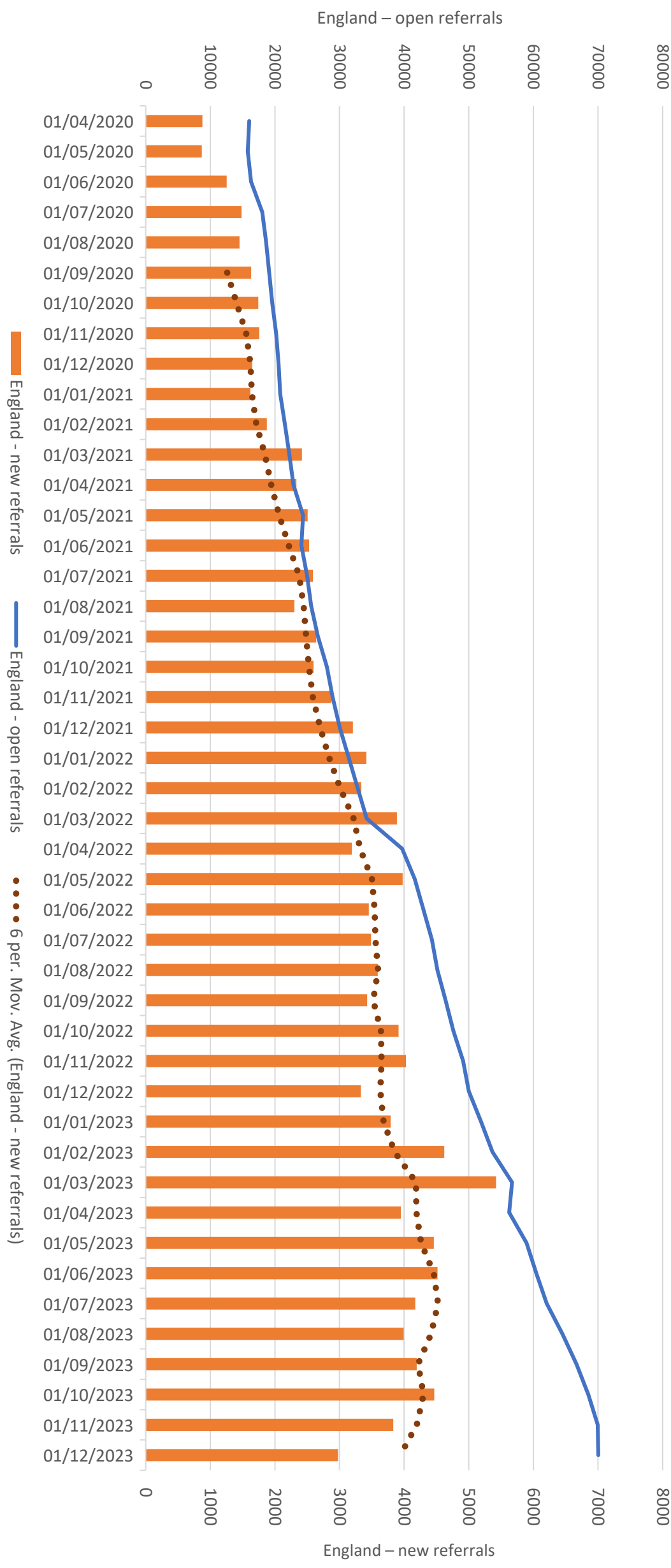


Being autistic does not mean you have an illness or disease. It means your brain works in a different way from other people. It's something you're born with. Signs of autism might be noticed when you're very young, or not until you're older. If you're autistic, you're autistic your whole life. Autism is not a medical condition with treatments or a "cure". But some people need support to help them with certain things.

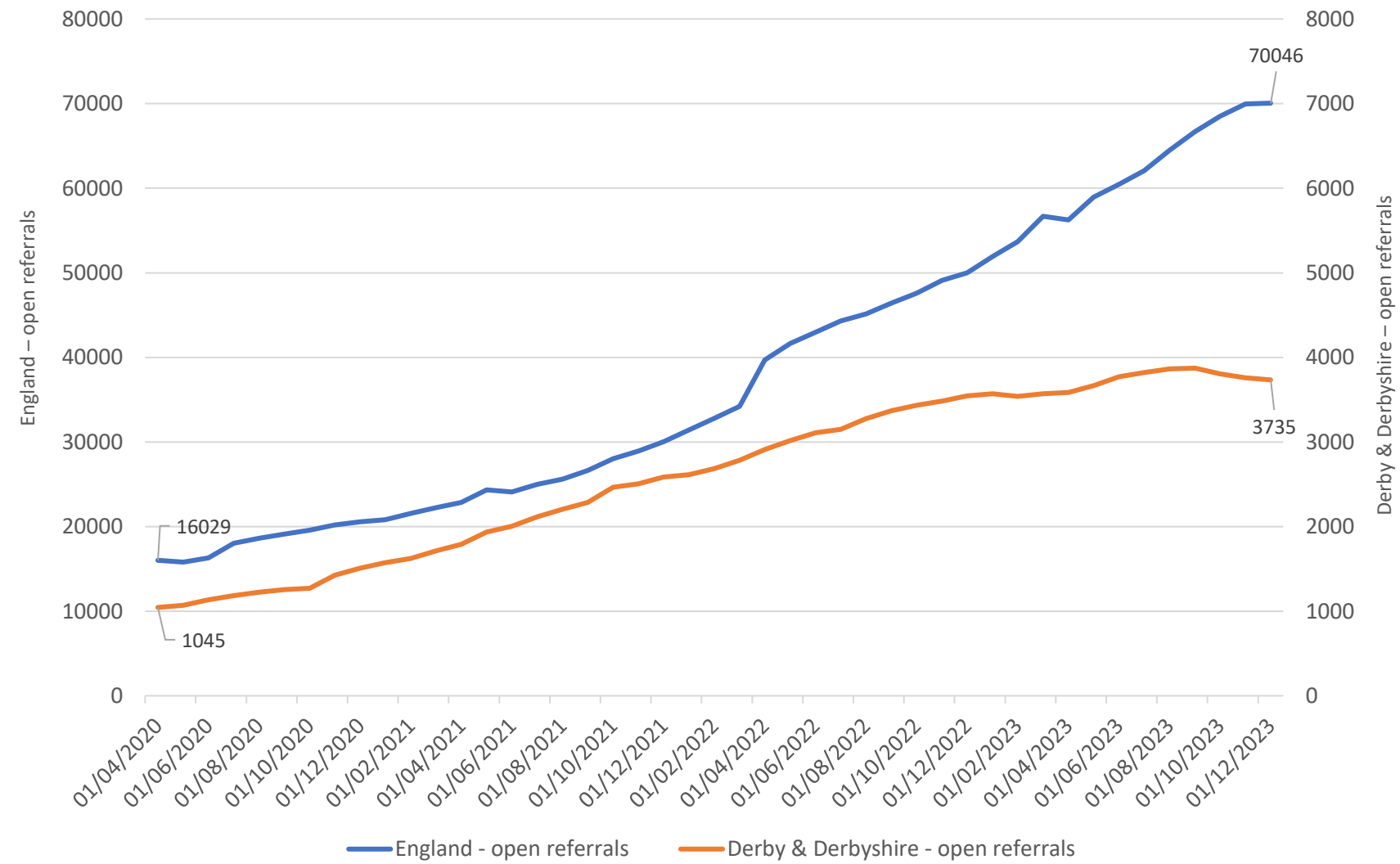
The importance of language

Some autistic people prefer 'identity-first' language. Some people with autism prefer 'person-first' language. When addressing groups typically it's safest to use identity-first language, as this is the preference of the majority of the autistic community. Most important is to understand & acknowledge people have different preferences & use their preference as much as possible.

Adults on the waiting list for an ASC diagnostic assessment



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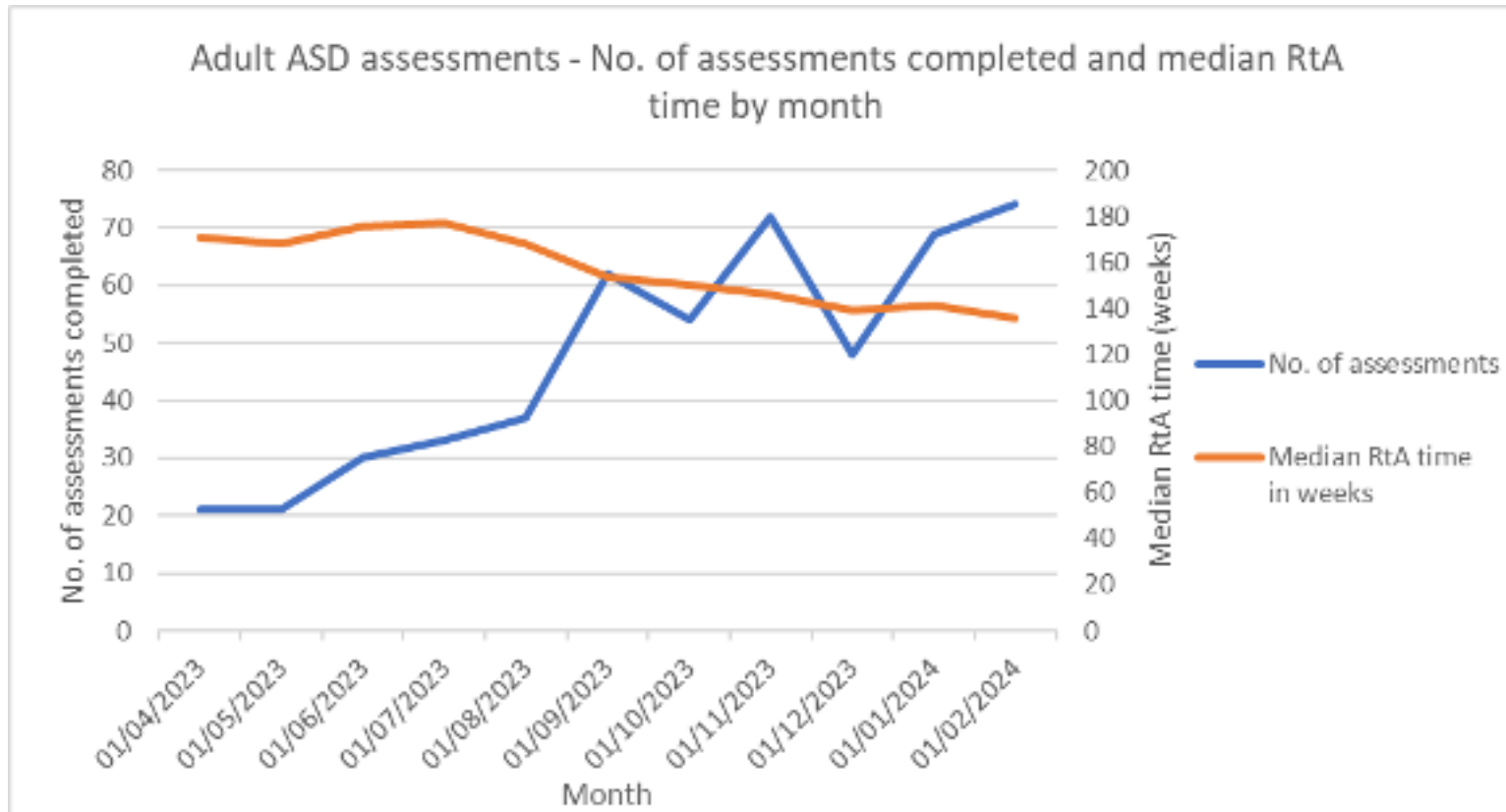


Date	England open referrals	JUCD open referrals	% of England open referrals
01/06/20	16,029	1,045	6.52%
01/12/20	20,570	1,510	7.34%
01/06/21	24,113	2,005	8.32%
01/12/21	30,034	2,585	8.61%
01/06/22	42,985	3,110	7.24%
01/12/22	49,997	3,545	7.09%
01/06/23	60,457	3,770	6.24%
01/12/23	70,046	3,735	5.33%

Improving performance – local NHS diagnostic services



Derbyshire Healthcare
NHS Foundation Trust



- Review of clinical processes have increased the number of diagnostic assessments completed.
 - more streamlined, with shorter appointment times & outcome reports.
- Data cleansing to ensure waiting lists are accurate.
- **Critically, no reported decrease in quality or service user satisfaction, with complaints & queries reduced further contributing to clinician's time being focused on assessments.**
- Sheffield Adult Autism & Neurodevelopmental Service have served notice on their contract with Derby & Derbyshire Integrated Care Board to deliver neurodivergent diagnostic assessments.
- The autism diagnostic assessment component is being re-directed into the local Derbyshire Healthcare service.

Right to Choose

Your choices in the NHS

Did you know that in many cases you have the legal right to choose where you have your NHS treatment? The NHS is offering more and more options to enable you to make choices that best suit your circumstances, giving you greater control of your care, and hopefully better results.

You can view what choices are currently available to NHS patients in the [NHS Choice Framework](#). Here you'll also find information about when you cannot choose – for example, if you need emergency care or you're a member of the armed forces. Make sure you know which options apply to you.

£1,800,000

Derby & Derbyshire Integrated Care Board's projected expenditure for 24/25 on ADHD & Autism diagnostic assessments for children & adults through 'Right to Choose' providers.

1,800

The potential number of diagnostic assessments this expenditure could commission.

2,132%

The growth in DDICB expenditure on one Right to Choose provider between 20/21 & 23/24.

There are some quality concerns regarding Right to Choose provision for neurodivergent diagnostic assessments. These have been raised with NHS England as to how these can be addressed at a national level.

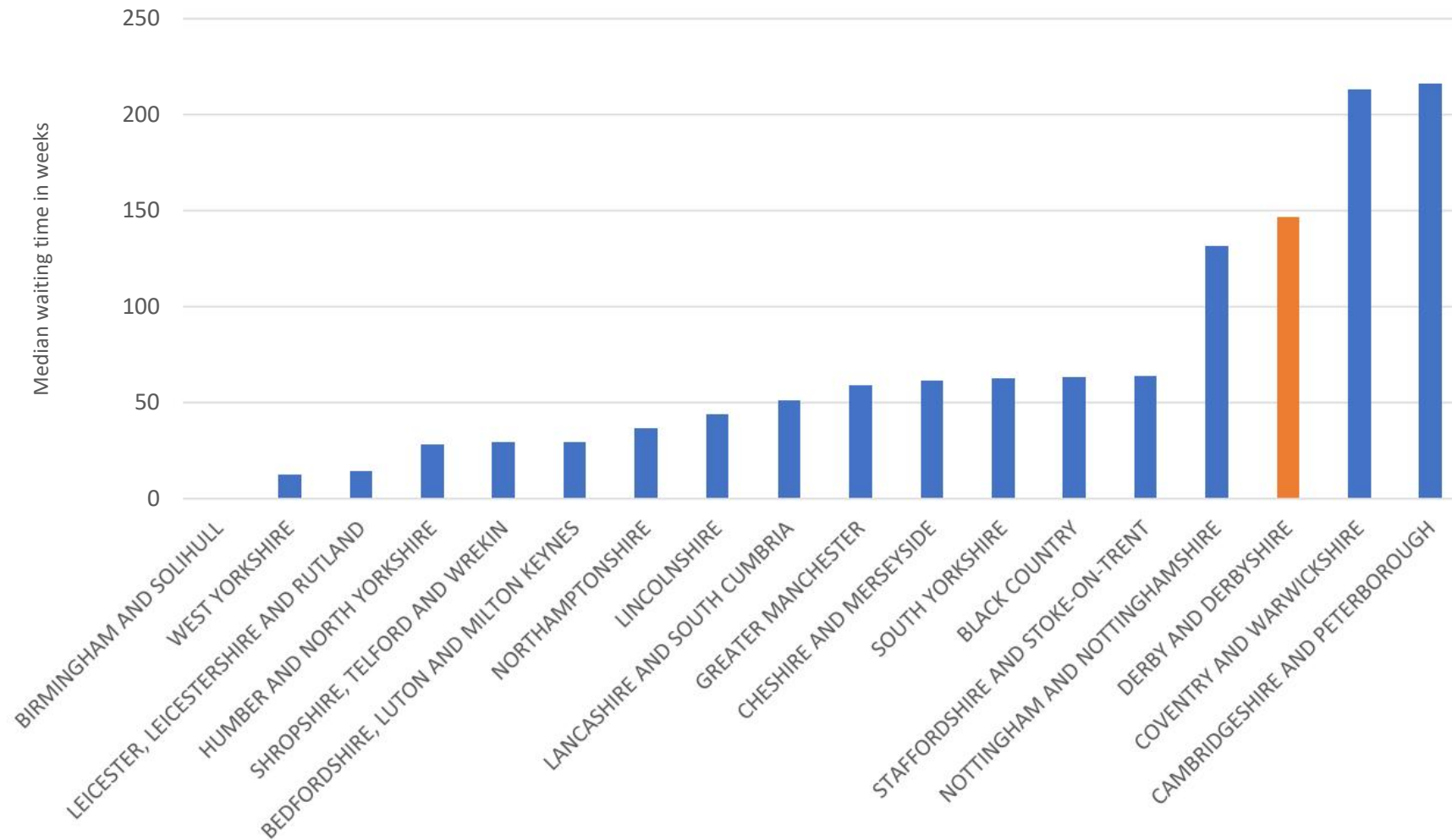
NOTICE TO PATIENTS

We continue to experience unprecedented demand for referrals for both our Adult ADHD and Autism services, which has inevitably created waiting lists for assessment and treatment.

Due to multiple factors, the time you will need to wait for an assessment can change frequently, so we are unable to offer precise timescales. Our call handling team are unable to give any more information on wait times over the phone; please wait to be contacted by us.

Waiting times

Median waiting time in days/weeks of patients aged 18 and over with an open suspected autism referral where their first care contact was in the quarter – NHS Digital Performance Metric



NHS cannot meet autism or ADHD demand, report says

12 5 days ago

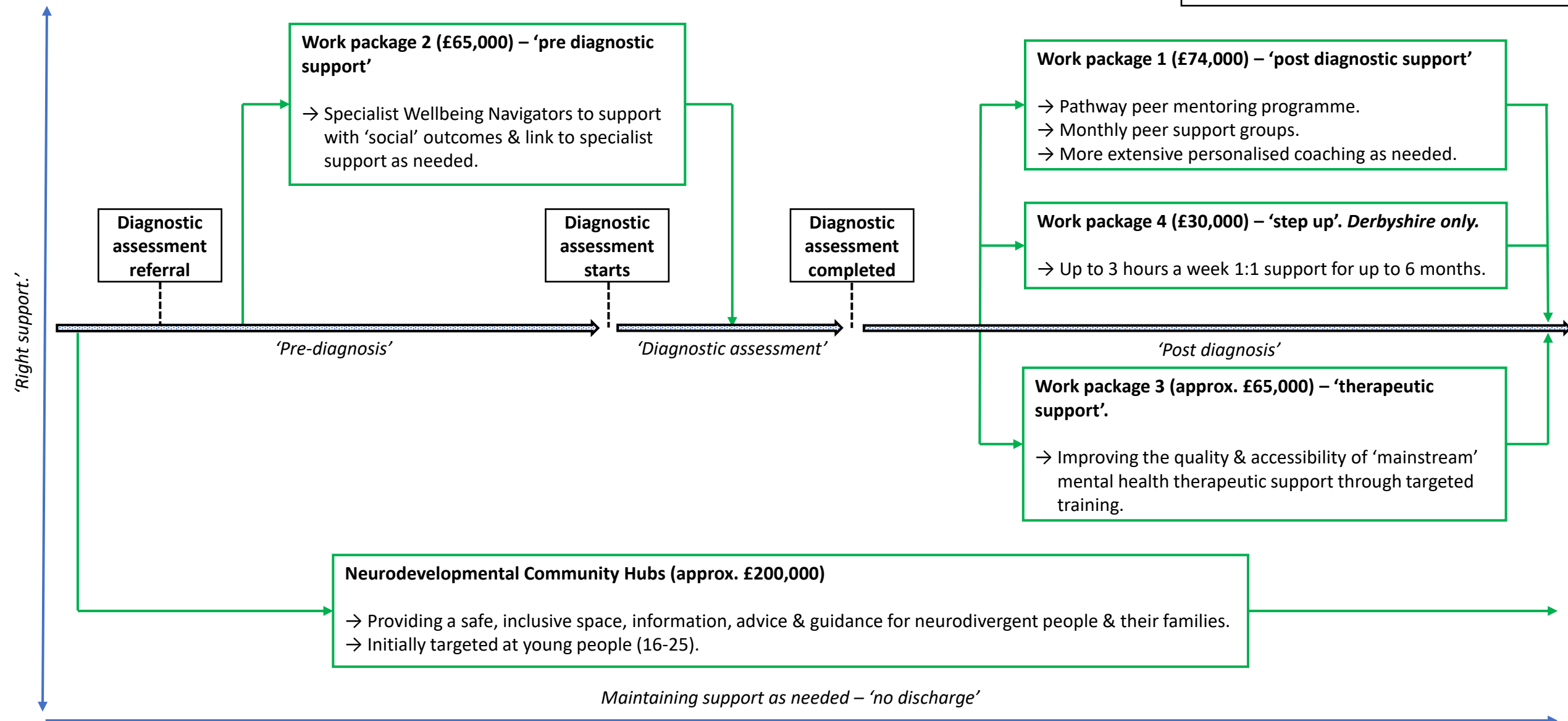
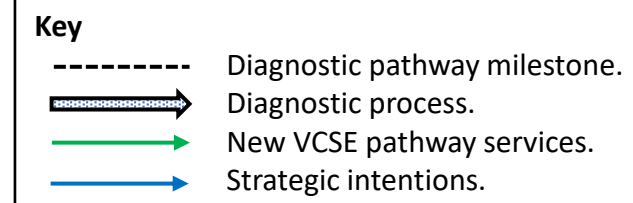


The NHS's Trust said long waits for autism assessments were especially damaging for children.

Between October and December 2023, the median time spent on a waiting list after an autism referral rose to over nine months, compared with four months in the same period in 2019.

And in Derbyshire, the waiting time was two and half years, according to the report.

The adult ASC diagnostic pathway



Neurodevelopmental Hubs



St. James Centre
Serving the Whole Community

Hub Opening Hours:
Calls, booked appointments and drop-ins
Monday - Thursday 10am-13:30pm
Friday 10am-13:00pm

Contact
Mob: 07561 856 320
Please try the mobile number first
Tel: 01332 604 080
Email: neurohub@stjamescentre.org

www.stjamescentrederby.co.uk
St James' Centre, Malcolm Street, Derby, DE23 8LU



- 4 Hubs across Derbyshire, lead providers are Citizens Advice Mid Mercia & Derbyshire Autism Services.
- Initial focus on support for children & young people (0-25) & their families.
- 380 Hub sessions hosted between April & December 2023.
- 425 people attended a hub in that period, 349 of those were children & young people:
 - 91% felt they better understood services
 - 99% felt more supported
 - 98% felt welcome & safe at the Hub.
- Information available on the Derby & Derbyshire Emotional Health & Wellbeing website.
- Derby City Hub opening hours
10:00 – 13:30 Mondays through Thursdays
10:00 – 13:00 Fridays

An ongoing challenge.

- Joined Up Care Derbyshire partners are dedicating significant financial & human resources into improving neurodivergent diagnostic pathways for children & adults.
- Unlike other NHS Long Term Plan & wider strategy/policy commitments, Integrated Care Boards have not received any significant additional funding to deliver these improvements.
- Furthermore, because of long waiting times for diagnostic assessments, it is not easy to re-invest Right to Choose funding into more local NHS led pathways.
- As the financial challenges faced across Integrated Care System partners continue to increase, difficult decisions are having to be made across competing priorities.

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