

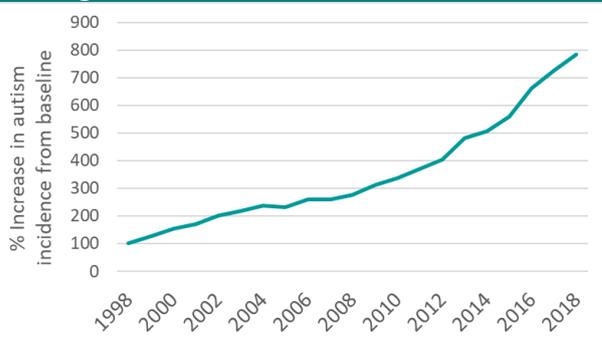
13 weeks? More like 3 years! The delay in autism diagnosis in the UK

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A BBC article recently reported, 130 children in Coventry and Warwickshire have been waiting 3-years for an autism diagnosis. The local NHS trust have expressed this is due to staff shortages and an increase in demand. They are receiving between 135 to 140 referrals a month, with a capacity to only deal with 60 to 64.¹

Over the past 20 years, there has been a **787% exponential increase in the incidence of autism in the UK²**, therefore...

Percentage increase in incidence of autism diagnosis from 1998 to 2018 in the UK²



Helen Stephenson

Member of Coventry and Warwickshire NHS trust¹

“Nobody is going to sit here and defend those waits. **We shouldn't have those waits.** But there is no quick fix and it **could take until April 2024** before the waiting times could be down to the **national target of 13 weeks**”

The UK has a national target for an autism diagnosis to be made in **13 weeks following referral**. According to the NHS, in quarter 2 in 2020-21 **only 15% of patients** with suspected autism had their first care contact, within 13-weeks of referral³

Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals⁴

Objective	<ul style="list-style-type: none"> ❖ To identify aspects of the autism diagnosis process that work well and that require improvement, in order to inform recommendations for service improvements. 	Themes and subthemes discussed by participants during the interviews
Methods	<ul style="list-style-type: none"> ➤ A qualitative interview study. ➤ The sample consisted of 10 adults with autism, 10 carers of children with autism and 10 healthcare professionals. ➤ Thematic synthesis was used to generate commonly discussed themes, from telephone interview manuscripts. 	<ul style="list-style-type: none"> • Range of initial concerns and routes to a diagnosis • Uncertainty in the features associated with autism • Vague and inconsistent routes to access diagnosis
Results	<ul style="list-style-type: none"> ✓ Three main themes were discussed by the participants, with multiple subthemes (listed on the right). ✓ A notable subtheme was the confusion in the route to diagnosis and the process involved. Participants experienced 'stark differences between clear and supportive pathways' for other conditions compared to the 'vague and inconsistent routes' with autism. ✓ One participant noted the need for a formal diagnosis to access employment or disability allowance or to access services and support. 	<ul style="list-style-type: none"> • Lack of awareness by HCP • HCP focus on negative aspects • Lack of rapport • Who is the expert? • Need for clarity • Spaces and assessments tailored to the patient's needs

Our thoughts:

- With the exponentially rising incidence of autism it is vital there is a robust structure to allow for **easily accessible diagnosis with adequate follow up support.**
- It is worrying that the 13-week referral target is not expected to be met for another 2 years, particularly due to the **likely further increase in demand.**
- The national shortage of clinicians and the impact of the COVID-19 pandemic have exacerbated the lack of capacity to deal with the demand for autism assessments. With a multitude of other impacting factors it's not a simple problem to solve.
- However, people cannot be waiting 3-years to receive a formal diagnosis, this is preventing access to vital services and financial support.

References

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2. Russell G, Stapley S, Newlove-Deigado T, Salmon A, White R, Warren F, et al. Time trends in autism diagnosis over 20 years: a UK population-based cohort study. *J Child Psychol Psychiatry*. (2021).
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