National Autistic Society

"Ending the Autism Diagnosis Waits Crisis"

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I will cover

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- The extent of the Autism Diagnosis Waits Crisis
- The Government's commitments to reduce the crisis
- What can be done to address the crisis focusing on Specialist Autism Teams
- Our #NowIKnow campaign

Autism diagnosis crisis

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- The latest NHS data shows that **over 120,000 people are waiting for an autism assessment** in England.
- This is a huge figure and an **increase of almost 40% in a year.**
- NICE guidance is clear – **no-one should wait longer than three months** between being referred and first being seen.
- But NHS data shows that the vast majority of people **(over 100,000 people) have waited longer than this.**
- It is a postcode lottery, which has **undoubtedly been made worse by the coronavirus pandemic.**

National Autism Strategy

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- In the National Autism Strategy published last year, The Government promised that by the end of the strategy (2026), demonstrable progress on reducing diagnosis waiting times will have been made and diagnostic pathways for children, young people and adults will have been improved across the country.
- In the Strategy the Government committed to:
  - investing £3.5 million to enable local systems to begin proactively identifying children and young people on waiting lists
  - invest £2.5 million of funding to improve the quality of adult diagnostic and post-diagnostic pathways, and help to address the impact of the COVID-19 pandemic on waiting lists
  - Significantly expand a school-based identification programme based on a pilot in Bradford from 10 to over 100 schools over the next 3 years.
  - invest £10.5 million to test and implement the most effective ways to reduce diagnosis waiting times for children and young people, the impact of the COVID-19 pandemic on waiting lists, and proactively identify those who are waiting for an assessment and are at risk of crisis

What can be done?

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- The Government committed to "making demonstrable progress on reducing diagnosis waiting times" in its national autism strategy for England. They must honour this promise and invest in rolling out diagnosis services across the country, as set out in the strategy.
- The commitments made only account for the first year (2021/22) of the strategy. For this to be a successful five-year strategy, it is critical that the Government provides the appropriate funding for the next few years.
- The National Institute for Health and Care Excellence (NICE) recommends that every locality has a 'Specialist Autism Team (SATs) ': an specialist autism, community-based, multidisciplinary service that is responsible for developing, co-ordinating and delivering care and support.
- SATs play a key role in carrying out effective diagnostic assessments, as well as offering information about appropriate services and support. So far SATs have only been developed in a few areas, we want to see them rolled out across the country.

Specialist Autism Teams

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- A recent study led by York University into the SATs that are currently operating, show it is eminently possible to set up such a service, despites so few localities achieving this so far.

- Study Findings support the notion of SATs and have demonstrated the benefits and positive impacts they can achieve; however, they need to be sufficiently resourced

- Twelve months after first using a SAT, there was evidence of a positive impact on people's mental health and ability to manage their daily lives.

- It also found evidence that people benefit most from SATs when these are made up of staff with diverse skills and professional backgrounds

#Now I Know

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- Attitudes towards autism and gender are changing, although we still have a long way to go. Many autistic women and girls are still struggling to get the support they need.
- Various studies suggest that the ratio of autistic males to females ranges from 2:1 to 16:1. The most-up-to-date estimate is 3:1.
- Autistic women and non-binary people are everywhere. Many go through life without knowing they are autistic. In our #Now I know campaign, we promote the stories, of Women and Non-Binary people, hearing in their own words how they have been affected by late diagnosis.

Dawn "I always knew who I was. Now I know why I am.“

Zahra "I can't change who I am. But I don't want to now."

Share your story on social media using #NowIKnow

Thank you!

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Any questions?

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