



Where Autism
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Why the wait? Autism diagnosis in the UK

Why the wait? That's the question the National Autistic Society (NAS) posed when launching their '[Autism Diagnosis Crisis](#)' campaign in August 2015. The aim of this campaign was to highlight the lengthy waiting times for autism diagnosis in the UK, with the goal of changing things for the better.

Diagnosis is important. Indeed, the NAS in the report [The way we are: autism in 2012](#) describes it as a 'critical milestone'. This is because receiving a diagnosis can enable parents to better understand their child, and can also provide access to crucial help and support. For those diagnosed as adults, the diagnosis is often a 'light bulb moment', providing an explanation for years of feeling 'different'.

But where is the evidence for these lengthy delays?

Back in the 1990s, Professor Patricia Howlin and Dr Anna Moore conducted a large-scale [survey](#) to gather parents' experiences of the autism diagnostic process. Surveying over 1200 parents, they found worrying delays of almost 4 years from when parents first sought professional help to the point at which a final diagnosis was received. It is therefore unsurprising that 49% of parents reported dissatisfaction with the autism diagnostic process. This was particularly true of

[parents of children diagnosed with Asperger syndrome](#)¹, who experienced greater delays and even higher levels of frustration.

Although Howlin and Moore's survey offered an excellent insight into the autism diagnostic process in the UK, and raised awareness of key issues (e.g., regional inconsistencies in services, the lack of post-diagnostic support), their survey was conducted in 1993 (over 20 years ago). Since then, there have been several smaller studies exploring aspects of the autism diagnostic process, together with some larger studies touching upon issues associated with diagnosis.

What has been lacking, however, is a detailed and comprehensive investigation into the current state of autism diagnosis in the UK. In 2011, we set up the Autism Diagnosis Project to address exactly this issue. A further aim of our project was to find out more about how different members of the autism community perceive the diagnostic process. This is because it is essential to gather a range of viewpoints on the key issues, rather than focusing on the experiences of parents alone.

Results from the Autism Diagnosis Project

Between 2011 and 2012, we set up three online surveys and had a fantastic response from:

- 1047 parents of autistic children;
- 128 autistic adults;
- 116 professionals involved in autism diagnosis (e.g., psychologists, psychiatrists, speech and language therapists).

Three key findings emerged from our surveys:

1. Waiting times

¹ Asperger syndrome is the term given to children and adults who show the core features of autism spectrum disorder (ASD), but do not display early language delays and have average or above average intelligence. Asperger syndrome was removed from the latest revision of one of the two manuals used to diagnose ASD (DSM-5; American Psychiatric Association, 2013). Yet, the term is used within this article to refer to children/adults who show the key features of ASD but who are verbally and intellectually able.

Reiterating the importance of the NAS Autism Diagnosis Crisis campaign, our results highlighted lengthy waits to obtain an autism diagnosis in the UK. Parents reported that they tended to wait around 3½ years before receiving an autism diagnosis for their child and (consistent with the results of Howlin and Moore) this delay was particularly pronounced for children who received a diagnosis of Asperger syndrome (who tended to wait over 4 years, compared to parents of children with autism who tended to wait 2½ to 3 years); this is probably due to the signs of autism being more subtle in these verbally and intellectually able children. Results from our adult sample also suggested lengthy waits to obtain a diagnosis, with an average delay of 2 years. However, there were suggestions that this was improving, with those adults diagnosed more recently experiencing shorter delays.

2. Satisfaction

More than half of the parents who responded to our survey (52%) were dissatisfied with the diagnostic process, and this was linked to waiting times (with those experiencing longer delays reporting higher levels of dissatisfaction). Whilst dissatisfaction was slightly less pronounced in our sample of autistic adults (40%), this was also linked to the time taken to receive a diagnosis. A positive diagnostic experience has been linked to greater levels of acceptance, lower levels of stress, and more effective coping strategies. It is therefore imperative that steps are taken to improve satisfaction with the process of receiving a diagnosis.

3. Post-diagnostic support

A key theme across all three of our groups – parents, adults and professionals – was that the support offered to autistic people and their families post-diagnosis was severely lacking. Professionals identified four key areas in which post-diagnostic improvements were needed: (1) the availability of the support offered by diagnostic services; (2) the availability of long-term support that diagnostic services can direct service users to; (3) streamlining support services (rather than offering a range of disjointed services that do

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not liaise with each other); and (4) providing specialist provision for under-served groups (e.g., adults without learning disabilities, autistic women).

What's next?

Around the time our surveys were being rolled out (2011-2012), the National Institute for Clinical Excellence (NICE) published guidelines for the diagnosis and management of [children](#) and [adults](#) with autism. These guidelines followed on from important pieces of legislation such as the [Autism Act \(2009\)](#), and the subsequent autism strategies ([Fulfilling and Rewarding Lives, 2010](#); then [Think Autism, 2014](#)). These formal commitments to improving the lives of autistic people will hopefully have an impact on the process of diagnosis too. Given all of these developments, it will be important to see whether the waiting times for autism diagnosis do decrease over the next five or ten years. Watch this space!

Read more about our research:

- Crane, L., Chester, J., Goddard, L., Henry, L.A., & Hill, E.L. (2016). [Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom](#). *Autism: The International Journal of Research and Practice*, 20(2), 153-162
- Jones, L., Goddard, L., Hill, E.L., Henry, L.A., & Crane, L. (2014). [Experiences of receiving an autism spectrum disorder diagnosis: A survey of adults in the United Kingdom](#). *Journal of Autism and Developmental Disorders*, 44(12), 3033-3044.
- Rogers, C., Goddard, L., Hill, E.L., Henry, L.A., & Crane, L. (2016). [Experiences of diagnosing autism spectrum disorder: a survey of professionals in the United Kingdom](#). *Autism: The International Journal of Research and Practice*

Or visit our website: www.autismdiagnosis.info