

Pathways to Diagnosis: From early years to later in life

From noticing early signs of autism in your child, to learning of your autism as an adult, this article will explore the journey through the diagnostic process.

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Prevalence of Autism Today

The prevalence of autism in the past decade or so suggests that there are more people being born and then later diagnosed with autism than ever before. When the first UK prevalence study was conducted 40 years ago, autism was thought to be a rare condition that occurred in 1 child per 2500. Today, [estimates](#) suggest at least 1 in 100 children have an autism spectrum condition.

A key reason for this is a growing knowledge of autism, including the recognition that children and adults can present with seemingly “less severe” or obvious symptoms, which were often difficult to identify at young ages. This led to the formulation of two new diagnostic categories that fall under the collective banner of [Autism Spectrum Conditions](#).

They are:

- [Asperger Syndrome](#) – begun to be formally diagnosed in 1994 - although no longer used as a diagnostic term.
- [Pathological Demand Avoidance](#) - identified in 2003.

In addition, there are socio-cultural influences that make it more likely for an individual to be diagnosed with autism today than in the past.

These include:

- An increased awareness and understanding of autism among parents, education providers, and health professionals.
- A lessening in the stigma associated with a diagnosis, for example dispelling the myth that autism is caused by “refrigerator mums” i.e. cold parents.
- An increased understanding of how autism affects women, which has seen an increase in diagnosis across the genders.
- The formation of specific autism diagnostic teams across the UK.
- The availability of governmental assistance specific to children and adults with an autism diagnosis.

Early Diagnosis

A child cannot be formally diagnosed until 18 months at the very earliest. However, according to the [NHS](#), a parent may begin to notice signs that their child is displaying signs of autism from as young as 2 months. Possible indicators within young children can include:

- Difference in speech development - for example a lack of babbling or delays in talking or differences in how language is used.
- Difference in social interactions - for example, interacting with toys in a rigid or repetitive way, or having limited eye contact.
- Sensory differences - for example, being highly stimulated by certain visual experiences or having unusual preferences about touching.
- Emotional or behavioural differences - for example, struggling with high levels of anxiety or problems regulating their emotions resulting in [meltdowns](#).

Rebecca, mother to Sadie 2, explains, *“I started to worry about Sadie’s development when she was about 16 months old. She’s my third daughter and I could see her development was different to her older sisters. She never pointed to anything, never lifted her arms to be picked up, didn’t respond to her name, wasn’t interested in other people and didn’t turn around when someone entered a room. Although she was very cuddly with me, she didn’t have any interest in playing with her sisters.”*

Some parents may worry about their children being labelled at such a young age and choose to delay pursuing a diagnosis. While it is understandable that families may be concerned, research shows early intervention is likely to produce the best outcomes for children on the autistic spectrum.

An early understanding of a child’s autism can also help parent’s bond with their child. As Dani Richman, a Specialist Autism Practitioner at BEAM in Barnet, explains, *“Early intervention provides parents with the opportunity to work with their child by using autism-specific, evidence-based approaches. This tends to help parents through the difficult process of acceptance.”*

A parent may be in denial about their child’s possible autism, due to perceived negative connotations, and therefore not address the possibility that their child may have the condition. In which case a nursery worker, GP or other health professional may detect a difference in the child’s development and suggest that the parent pursues a referral for an assessment.

Step One: Referral for an Assessment

If a parent or specialist detects a child displaying signs of autism, they should seek advice from one of the following professionals in order to arrange an autism assessment.

- A GP
- A health visitor (for children under 5)
- Any other health professional you or your child see, such as a speech and language therapist
- Special educational needs (SENCO) staff at your child's school

An assessment will then be carried out by an autism specialist via the NHS. Although the [NICE guidelines](#) states that an assessment should be offered within three months of a referral, the waiting list for a diagnosis is dependent on the local authority and generally takes up to two years.

Some families may opt for a private diagnosis, which can cost anywhere from £1,000 - £2,500. A private diagnosis can happen within weeks of a referral but it is not always recognised by public services when presented as evidence by parents seeking entitlements to statutory support from education, health and social care. Some parents therefore opt for a private diagnosis of autism but continue to stay on the NHS waiting list.

Ben, father to Harry 7 tells us, *“We have been waiting for over a year for Harry to be assessed and based on current waiting lists we have at least another year to wait. Without a formal diagnosis we can’t start to access support for our son – support to get funding, or more help at school, to get therapy and respite for the family but also support for us to finally come to terms emotionally for what we are about to embark on. It’s heartbreaking waiting to start on what we know will be a long road.”*

Step Two: The Assessment

When a child is being diagnosed, there is a diagnostic team comprised of people from different professions. The assessment takes place over a number of days. Different diagnosticians use a range of methods to diagnose autism, but there are [guidelines](#) that they should follow.

During the assessment, the team will look at all information pertaining to a variety of settings, for example at nursery or in school. They will explore an autism-specific developmental checklist as well as looking at family history. They will also partake in observations on the child in these various settings. They will assess communication, behaviour and overall mental health assessments to formulate a diagnostic report. This will detail the child’s diagnosis of autism and provide a profile of their needs.

The characteristics of autism vary from one person to another. In order for a diagnosis to be made, though, the child will usually be assessed as having had:

- Persistent difficulties with social communication and social interaction

- Restricted and repetitive patterns of behaviors, activities or interests
- Sensory differences

These difficulties will have been present since early childhood and will have affected the child's daily life.

Step Three: Accessing Services

An early diagnosis is key in allowing children with autism to thrive. It enables children and their families to access specific support, and it ensures that as much as possible is in place when the child starts compulsory education.

Local Authorities have a statutory duty to create an education, health, and care (EHC) Plan for children and young people aged up to 25 who need more support than is available through the special educational needs support provided by individual schools. EHC Plans identify educational, health, and social needs and set out the additional support to meet those needs which may include the child accessing a support worker or assistant within the school setting.

Some local authorities have specialist early intervention provisions. For example, BEAM (Barnet Early Autism Model) in Barnet has been designed for families of pre-school children under five with a confirmed diagnosis of autism. BEAM acts as an early intervention service, based in the home, where families receive home visits from a trained autism specialist facilitator who teaches and model strategies through structured activities that are based on the needs of the individual child. The intervention focuses on social communication skills, attention skills, play skills, emotional regulation (related to behaviour), and educational skills.

An early diagnosis can also make parents aware of additional support they may be entitled to, including [respite services](#) and [advocacy services](#) to help them navigate what can be a complicated system of public services provision.

Late Diagnosis in Adults

There are an increasing number of adults whose autism was missed as a child and who are now being diagnosed after a lifetime of challenges and feeling "different" but not knowing why. This is mainly due to an historic lack of autism knowledge as professionals did not identify less extreme characteristics in individuals.

Another reason is the increase in female diagnosis. Until recently, it was thought that autism predominantly affected boys and men at a much higher rate compared to women. However, [new evidence](#) suggests that the condition has been largely underestimated in females, with the most-up-to-date estimate putting the ratio at 3:1.

Due to these early misconceptions, studies have tended to overlook females to focus on males, leading to a gender bias in the research. Doctors, teachers, and parents alike primarily linked the condition to males so they were less likely to identify signs in females. In addition, because women are known to have inherently better social skills, they are more adept at masking certain behaviours to fit in with their peers – which also meant their autism went undiagnosed.

As a result, many women and girls have been diagnosed later in life, as a result of their child receiving a diagnosis or after a mental health crisis. While some have had their autism misdiagnosed completely. Without a formal diagnosis, they are at an increased risk of mental health problems such as depression, eating disorders, and self-harm as a result of a lifetime of feeling different and being unable to access autism specific support.

However, there are also a growing number of female only autism groups and services emerging. An innovative example is a Mothers Autism group that Resources for Autism deliver yearly for mothers on the autism spectrum who wish to connect with others forming a peer support network and life-long friendships.

Mixed Emotions

After receiving a diagnosis, people tend to feel a mixture of emotions. There may be relief at finally being understood and the ability to access support. However, late diagnosis can also include feelings of loss, remorse, and shame around missed support and wasted time, as well as a sense of being let down by professionals and family over the years.

Eve was diagnosed at 42 years old. As she explains, *“Being diagnosed is like getting my Hogwarts letter. Instead of feeling intense shame about who I was and how I behaved, I had an answer about why I was different and could start to see all the strengths I have from my neurodiversity. It also meant I could meet people who are like me, and I could start to work on the areas of life I have struggled with.”*

Next Steps for Adults

The Autism Act was introduced in 2009 to improve support for adults with autism. This required the Government to produce a strategy for improving services for autistic adults, underpinned by legally binding guidance to councils. Because of the Act, almost every council has a diagnosis pathway for adults which should be based on [NICE guidelines](#). Additionally, it makes sure that every autistic person has the right to a social care assessment, something which was difficult for many autistic people more than 10 years ago.

Once an adult’s possible autism is picked up they have the option of going down the private or NHS assessment route. More recently, some boroughs have begun to offer an [autism screening service](#) for anyone with suspected autism which acts as the first step in the NHS pathway. This can be an incredibly useful tool for adults to explore possible diagnosis in a less intrusive environment.

During an adult assessment, the assessor will ask a range of questions in relation to the adult’s childhood history. They may look at any reports from their GP or mental health services and they may talk to someone from the adult’s life, such as a sibling, to gain a broader picture of the individual’s challenges. The assessor will also observe how the adult interacts, as well as their use of nonverbal communication. They will also assess the adult’s sensory needs.

Once an adult is diagnosed, they are able to access specific autism support and services. If they are in employment they are eligible for [Access to Work](#) in order to fund adaptations or workplace support to assist them in their job. And they are subsequently protected against discrimination under the [Equality Act \(2010\)](#) if they choose to diagnose their autism.

For Eve, these specialist professional services have been hugely helpful. *“Being heard and understood by someone who ‘gets’ autism has made my life so much better,” she says. “I am now able to thrive at work and in my relationships and I no longer feel ashamed or confused by my differences.”*

For more information on autism and for specialist services visit -

<https://resourcesforautism.org.uk/>