Improving the diagnosis of autism spectrum disorder

ANGELA DOWDEN

Delays in the diagnosis of autism spectrum disorder (ASD) in children and young people are all too common and cause real anguish for those affected and their families. This article assesses the scale of the problem and discusses possible reasons and solutions.

The NICE clinical guideline Autism Spectrum Disorder in Under 19s: Recognition, Referral and Diagnosis (CG128) states that a diagnostic assessment for autism should occur within three months of referral to the autism team. But a freedom of information (FOI) request sent to NHS mental health trusts in England and reported in The Guardian in July 2018 found waiting times much longer – at the Berkshire Healthcare NHS Foundation Trust, for example, under-18s waited an average of 574 days for their first appointment.

The problem is worse when the sometimes very drawn out process of assessment is added in. For example, the Guardian FOI request revealed that at the Somerset Partnership NHS Foundation Trust, the total time from referral to official diagnosis was in one case 196 weeks (nearly four years) for a child.

These findings fit broadly with those from the Autism Diagnosis Project, which collected data between 2011 and 2012: it found that on average, parents tended
to wait around three and a half years between the time they first flagged up problems with a GP or health visitor, and receiving an autism spectrum disorder (ASD) diagnosis for their child. In addition, most parents waited a year after their first suspicion something might not be right before making any approach. Those given the diagnosis of Asperger’s syndrome tended to experience longer delays (over four years) than children who were given a diagnosis of autism (between two and three years). This may be related to the signs of autism being subtler in children who do not have intellectual impairments and who appear to show good language abilities.

The unacceptable wait for patients and their carers has been highlighted by the BMA. At its annual conference in June 2018, the association’s Annual Representatives Meeting (ARM) backed a motion expressing disappointment at “the disparity in waiting times for referral, assessment and the diagnosis of autism”. The BMA called upon NICE to produce clearer guidance on the acceptable waiting times from referral to diagnosis when autism is suspected.

**Funding and organisational problems**

According to BMA Consultants Committee Deputy Chair, and Child and Adolescent Psychiatrist Dr Gary Wannan, autism services have suffered the same chronic underinvestment as mental health services in past years, and it is this underfunding that has led to families of people with autism waiting years for their relative to get the help they need. “There have been reassurances about funding autism services but, as these figures show, doctors are concerned whether this actually reaches patients on the frontline,” says Dr Wannan.

Tim Nicholls, the National Autistic Society’s Policy Manager agrees: “Once they have a referral, people have to wait too long – sometimes years – for an assessment. This is down to capacity, with not enough trained professionals in [the field] to make a diagnosis.

“Awareness of autism is increasing and many more people will think that they might be autistic. Local commissioners need the resource to meet this demand, otherwise potentially autistic people will struggle without the vital support that an autism diagnosis can help unlock.”

But though funding ultimately underpins the effectiveness or otherwise of all aspects of autism referral and diagnosis, it’s a complicated situation, not helped by inadequate policy frameworks. In an autism self-assessment exercise carried out by local authorities in England between July and November 2016, only 52% of local authorities gave themselves the highest (green) rating for their establishment of a local diagnostic pathway. In 33% of local authorities, there was no report of having a specialist autism-specific service, while only just over a fifth (22%) of local authorities reported meeting the NICE recommended waiting times.

Organisational complexities also have a role in how autism strategy plays itself out for patients living in different areas: for the majority (104; 68%) of local authorities in England, co-working with NHS CCGs is helped by having a simple relationship of one local authority to one CCG; however, 41 local authorities (27%) relate to more than one CCG and 15 local authorities (10%) work with four or more CCGs.

**Are health professionals creating barriers?**

Sometimes even getting the critical referral to a paediatrician or the autism team for assessment in the first place can be a fraught process. Says Tim Nicholls: “Autistic people and their families tell us that they face issues in getting a referral, perhaps because the professional who needs to make a referral doesn’t think it is necessary. This can often be down to a lack of understanding of autism.”

It’s a situation that chimes with Sally, mother to George. She explains: “I had been taking my son to the GP saying something was wrong since he was three years old. Eventually, they referred me to a place called First Steps, where he saw a child psychologist who did six sessions with us and then discharged him saying he just needed to be treated with ‘extra sensitivity’, whatever that means. That was when he was about five years old. We continued having huge problems with his behaviour at home and at school. I went back to the GP who referred us to our local CAMHS [Child and Adolescent Mental Health Services], where he saw a psychotherapist who told me emphatically she didn’t believe he had ASD. It took until he was eight years old to finally get a diagnosis. He has both ASD and ADHD [attention deficit hyperactivity disorder]. Those years when we didn’t know were extremely difficult. He was getting into trouble a lot rather than having some understanding that there was a diagnosis at the root of things. The difference of opinion between medical professionals really surprised me. It’s much easier now as we now have an EHCP [Education, Health and Care Plan] in place and have done many things to help knowing that he has ASD and ADHD.”

**Pushy parents?**

According to the charity Ambitious About Autism, some GPs are very co-operative when a parent asks for an autism referral for their child (especially if the practice records have already picked up some indicators in the regular check-ups). But others may be less helpful if they don’t see the signs in the child themselves. The advice the charity offers on their website is for parents to “develop a talent for making a polite nuisance of themselves (more properly known as ‘advocacy’)”.

However, there is a fine line between advocacy and parental pushiness that doesn’t help anybody if it’s crossed. Ambitious About Autism say medical professionals will usually be unwilling to diagnose a child under two years

<table>
<thead>
<tr>
<th><strong>Table 1. Number cruncher: the costs of diagnosing and treating autism.</strong> Figures taken from: Galliver M, et al.5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>£809:</strong> Median cost for diagnosing autism in a child (based on 13 hours of professional time spent)</td>
</tr>
<tr>
<td><strong>£25,400:</strong> Average cost per year of supporting a child with autism in the UK</td>
</tr>
<tr>
<td><strong>£2.7 billion:</strong> Estimated annual support bill for all childhood autism in the UK</td>
</tr>
<tr>
<td><strong>£25 billion:</strong> Estimated annual support bill for all adults with autism in the UK</td>
</tr>
<tr>
<td><strong>£1.1 million:</strong> Modelled potential lifetime savings (per patient) when there is effective early intervention for autism</td>
</tr>
</tbody>
</table>
old because toddlers tend to have limited language and social skills at this age even if they’re neurotypical. While acknowledging that it’s frustrating if you think your child is on the spectrum but a paediatrician refuses to diagnose them, they remind parents that doctors have to be careful, as the wrong label can have serious consequences.

Ultimately, whether a child gets a diagnosis of autism shouldn’t matter too much, as if a child is having clear difficulties, parents can still apply for help, such as an EHCP, on the strength of that. But while barriers to a more expedited autism diagnosis process remain, there’s still often much stress for children and parents along the way.

Is any progress being made?
One potentially big step forward is that since April 2018 – following a three-year National Autistic Society campaign – the government has at last started collecting data on autism diagnosis.

“Local areas are now required to collect vital data about autism diagnosis and that means that we will soon know how long people are having to wait across England,” says Tim Nicholls. The data will take a while to build up and be published, but the government has said that it hopes the first publication of this data will happen in summer 2019. “In the meantime, we will carry on campaigning because, while having the data is important, in order to tackle the crisis, we need to make sure it is used by government to hold local areas accountable for driving down waiting times,” he adds.

In another strand of research, scientists have been making the first steps towards what could potentially become a blood and urine test for autism, based on the finding that children with ASD have increased advanced glycation end products (AGEs) and increased amounts of the oxidative damage marker, dityrosine, in plasma protein compared with healthy controls. In any such biochemical test to ‘detect’ ASD is fraught with complication and a long way off and, for now, diagnosis still centres largely around the objective opinion of an expert in the field, supported by standardised tests. Even with the best will in the world, this is a route that can rarely be hurried.

References

Declaration of interests
None to declare.

Angela Dowden is a freelance journalist and registered nutritionist