

## Evidence Briefing #17



### Barriers to obtaining a diagnosis of learning disabilities and/or autism

#### The Issue

The Integrated Care Board (ICB) has asked commissioners to support the production of a mandated dynamic support register (DSR) of people with learning disabilities and/or autism who need support and may be at risk of an admission to hospital.<sup>1</sup> People can ask to be on the register and they have to consent to be included. Each local area publishes their own criteria for inclusion in the register and decides whether a formal diagnosis is required. There is a long wait for diagnostic services in Bristol and commissioners wanted to know whether this was the only barrier to diagnosis before deciding on what local criteria to establish for inclusion on the register.

#### What we wanted to find out

What are the barriers to obtaining a diagnosis of learning disabilities and/or autism and how does having a diagnosis affect access to services?

#### What we did

We searched for relevant reviews and research studies using multiple terms for autism and learning disabilities. We searched NIHR and Cochrane library resources, and SCOPUS and Medline databases.

We focussed on studies and reviews including adult participants in the UK.

#### What we found

We did not find any studies on receiving a diagnosis of learning disabilities as an adult. This is unsurprising as one of the criteria for a diagnosis of a learning disability in the UK is that the onset was in childhood<sup>2</sup> and diagnosis may be identified at birth or as children develop.

We found two systematic reviews of qualitative research, one exploring the views of autistic adults in the UK,<sup>3</sup> and another focused on the views of health professionals involved in the diagnosis of autism, which included studies conducted in the UK<sup>4</sup>. We found a survey of 128 autistic adults' experiences of obtaining a diagnosis in the UK,<sup>5</sup> and a mixed methods study consisting of secondary analysis of a qualitative study that then formed the basis of a quantitative survey that was conducted in the USA, Canada and the UK.<sup>6</sup>

#### What the evidence suggests

##### Barriers to a diagnosis of autism

- Social anxiety, can sometimes make it difficult for autistic people to make, travel to and attend an appointment to begin the process of obtaining a diagnosis. The most frequent and most severe barrier identified, particularly for women, was the fear of not being believed<sup>6</sup>.
- Stigma can be a barrier to diagnosis. Some people with autism feel misunderstood due to a perceived limited understanding of autism by professionals, who base their knowledge on unhelpful stereotypes. Family members and people themselves can be a barrier to diagnosis due to negative associations with autism as a mental illness.<sup>3,5</sup>
- Mistrust of professionals can prevent people seeking a diagnosis, due to past experience and describe feeling like they were 'passed from pillar to post' by professionals unclear of an appropriate referral pathway to diagnosis<sup>6</sup>.

- Language and cultural differences and inadequate time given to complete assessments contribute to barriers to completing the diagnostic process<sup>4</sup>. Women report barriers to diagnosis due to their learned coping strategy of camouflaging their social communication difficulties<sup>3,5</sup>
- The focus on deficits can mean some people find assessments for autism a negative process. As some assessments are designed for children rather than adults,<sup>3</sup> autistic adults sometimes feel patronised. Health professionals recognise that assessment tools are not ‘subtle’ enough for the presentation of autism by some people.

Health professionals are aware of the high demand for services, and<sup>4</sup> long waiting times are the most frequently cited barrier to diagnosis in the UK.<sup>6</sup> Longer waiting times are associated with reduced satisfaction in the diagnostic process.<sup>5</sup>

Some people do not seek a formal diagnosis due to being told that there is no benefit to obtaining a diagnosis as there are few services available for adults with a diagnosis<sup>6</sup>.

Some people do not seek a diagnosis because they are confident that they have autism without a formal diagnosis.<sup>6</sup>

### Access to services

In the one study that examined the support available to adults following a diagnosis of autism, 42% did not receive any support. People cited counselling, social skills training and access to support groups as services that they would benefit from<sup>5</sup>.

Health professionals have described a diagnosis as an ‘entry ticket’ to services for some people<sup>4</sup>. Diagnosis has assisted some people with autism to receive additional support at work or education or receive help from social care. With a diagnosis some people felt validated and a sense of connection of others in the autistic community<sup>3</sup>.

### Quality of the evidence

The research included represents the experience of diagnosing or being diagnosed with autism in the UK. The perspectives of people with autism are based on analyses of a selection of small studies or online surveys. As such, they only represent those who are able to contribute by those methods.

### For more information about this briefing, contact

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### References

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