New Scottish guidelines on the diagnosis of autism in adults

New guidelines on ‘Assessment, diagnosis and interventions for autism spectrum disorders’ have been published by the Scottish Intercollegiate Guidelines Network (SIGN), the body which develops clinical practice guidelines for the NHS in Scotland. These new guidelines now include evidence for adults and older people.

The National Autistic Society Scotland have long been campaigning for better recognition of autism among adults and for many years have called for action to improve the diagnostic process for autistic adults. As a result, the Scottish Strategy for Autism included a recommendation for SIGN to produce guidelines on assessing, diagnosing and managing autism in adults.

We therefore particularly welcome that the new guidelines cover all ages and replace previous guidelines that only covered children and young people. This should make it easier for autistic adults in Scotland to receive a diagnosis and access support as doctors, consultants and other clinicians will now be able to refer to the guidelines for information on best practice and what approaches, therapies and interventions are recommended. SIGN is currently working on a number of information booklets for adults, patients, carers and young people which will allow individuals without a medical background to better understand the guidelines and what to expect when seeking a diagnosis.
For the first time, these guidelines acknowledge that autism can present differently in women and girls. This is something that we have highlighted in the past and we welcome the useful references provided in the guidelines. We believe that they will improve the chances of women and girls receiving a correct diagnosis.

**Waiting times**

Currently in Scotland there are no autism-specific waiting times targets, although there are relevant targets in place such as the 12-week outpatient appointment target and the 18-week referral to treatment target.

The [National Institute for Health and Care Excellence](https://www.nice.org.uk) (NICE) performs a similar function to SIGN for England (and to some extent for Wales and Northern Ireland), and makes clear that no patient should have to wait longer than three months between a referral for diagnosis and first appointment. The SIGN guidelines do not include a recommendation on waiting time targets for diagnosis, as waiting times policies are set by the Scottish Government.

There is however, a recommended maximum waiting time of 119 days from having an initial referral to sharing a diagnosis, which is used as a target to measure performance against. A [study published by the Autism Achieve Alliance](https://www.autismachieve.org.uk) in 2014 identified that 59 per cent of adults and 74 per cent of children took longer than 119 days to receive a diagnosis and that the average diagnosis waiting time for children was 331 days, with the longest individual case in their study taking over five years.

In light of this, we believe that the Scottish Government should implement a [Local Delivery Plan](https://www.gov.scot/Topics/Health/Improvement/LocalDeliveryPlan) (LDP) for autism to join the many others that are currently in place, such as dementia post-diagnostic support and smoking cessation.

We believe it is incredibly important that diagnosis waiting times are set for Scotland because a diagnosis can be a gateway to services and support, and early intervention and support can help prevent the development of more complex needs. Autistic individuals and parents also regularly
tell us of the great relief they feel on getting a diagnosis and describe the stress they experience in waiting for an assessment.

We will therefore be working with autistic people, their families and others to call for an autism-specific LDP. An LDP along with the Scottish Strategy for Autism and the new SIGN guidelines would help substantially reduce waiting times and improve access to services for autistic people of all ages.

Further reading

The National Autistic Society, Autism diagnosis for adults