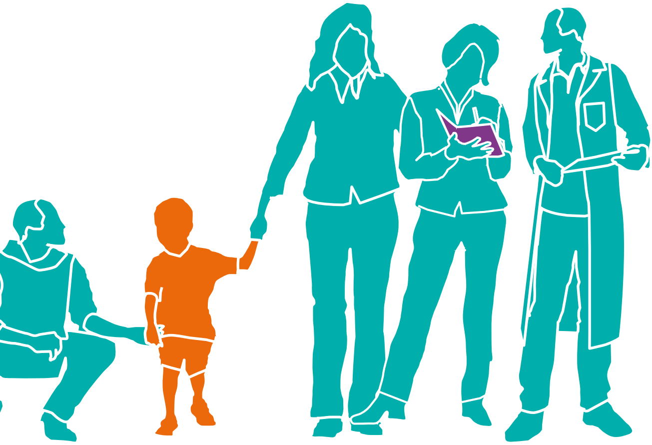
How is ASD diagnosed?

New Zealand Autism Spectrum Disorder Guideline



A resource
to help identify
autism spectrum
disorder

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Information in this resource is drawn from 'New Zealand Autism Spectrum Disorder Guideline' (NZ ASD Guideline). The guideline is available online at www.nzgg.org.nz – search term: autism.

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Promoting Effective Health and Disability Services

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1 Who is this for?

This resource is for people who work in education, health or community settings who might come across children or adults with possible ASD or who might refer someone on for further assessment or diagnosis.

It describes the process of formal diagnosis of ASD, so that both you and the person with possible ASD and their family/whānau know what to expect if the person is referred for formal diagnosis.

There are two companion resources in this series:

- **'What does ASD look like?'**
  A resource to help people in education, health and community settings identify signs that may indicate ASD, and decide what action to take.
- **'Does this person have ASD?'**
  A resource for the professionals who will make an initial assessment and then may refer the person on for specialist diagnosis.

There is some overlap of information in these resources.

2 How to access diagnosis

Most publicly funded, specialist diagnostic services accept referrals only from doctors (usually GPs) and sometimes from other professionals, including:

- psychologists, Resource Teachers: Learning and Behaviour (RTLBs), teachers, speech-language therapists, public health nurses and Plunket nurses.

Currently, publicly funded diagnostic services exist only for children and adolescents, and for adults who have an intellectual disability. While the New Zealand Autism Spectrum Disorder Guideline (NZ ASD Guideline) recommends that specialist diagnostic assessment should be publicly available for all people who may have ASD, this is not currently the case.

Most private diagnostic services accept self-referrals and referrals from agencies, including referrals of adults.

Contact Altogether Autism or Autism New Zealand (see page 12 for contact details) or information about private services.

Formal diagnosis not always essential

It is important to remember that not all people who could have ASD want or need formal diagnosis. Some people:

- manage their lives successfully without thinking or acknowledging that they might have ASD
- are so well supported by family/whānau, friends and others that formal diagnosis is unnecessary and would not benefit them
- are happy with who they are and their lives, and do not want to be formally diagnosed
- will find the process of diagnosis, which will require several visits to see new people in unfamiliar places, and some medical procedures, very challenging.

People and families/whānau can review or change their decision regarding diagnosis at any stage.

They can also seek information about ASD through organisations such as Altogether Autism or Autism New Zealand. Any person can access information, whether they have been diagnosed or not.

A child does not need a diagnosis to access early intervention or other educational services from the Ministry of Education.

> “I am proud of who I am and autism is part of who I am. In fact, you can’t separate the autism from what I do, think or am.”

3 Diagnosis: what is it?

Diagnosis is a process used to identify a disease or condition. It comes at the end of an assessment process, which involves examining the patient's history, symptoms and appearance, and analysing diagnostic tests. For people with ASD it requires a process of observation and clinical examination that can take some time.

Part of making a diagnosis is called differential diagnosis. This is the medical term for the process of excluding all the other possible conditions that could cause the same symptoms. There are often other conditions that occur as well as ASD. This can make diagnosis a complex process.

4 Who does it?

The ideal team for making an ASD diagnosis is multidisciplinary, comprising at least two or three members of the following professional groups:

- paediatrician
- psychiatrist
- psychologist
- speech-language therapist
- occupational therapist.

In areas where there is no multidisciplinary team, a paediatrician (ideally a specialist developmental paediatrician), psychiatrist or clinical psychologist might undertake the diagnostic assessment.

All professionals who assess for an ASD diagnosis, in addition to their professional qualifications, should have expertise in ASD and related conditions acquired through ASD-specific training, professional development, supervision and work experience.

5 What is the process?

Core components of assessment:

- interviews with the person (at an appropriate level for their age) and their family/whānau to obtain:
  - information about their development
  - any relevant family history.
- observing the child or person:
  - in different settings (such as home, school, etc) looking at communication, social and play/leisure skills in structured and unstructured settings.
- medical evaluation:
  - history
  - undertaking or arranging for appropriate medical tests
  - comprehensive record and file review.
- assessments of:
  - intellectual functioning
  - communication skills
  - mental health and behaviour problems
  - family resources and needs.
- interviews with others, including (where relevant):
  - early childhood educators or school teachers to obtain information about the child in the classroom and playground.

Additional components: Other things which might be assessed include:

- social and emotional abilities
- adaptive functioning (life skills)
- cognitive abilities
- neurological abilities
- vision and hearing
- sensory and motor (movement) abilities
- occupational therapy and physiotherapy needs
- personal interests and activities.

Report: After all this information has been collected and analysed, a report is written which will outline the results of all these assessments and may also include:

- the diagnosis (whether or not the person has ASD, a different disorder and/or any other conditions)
- recommendations such as:
  - specific information about how ASD affects this person
  - the person's eligibility for various services or benefits.
- interventions and effective strategies
- any medication
- family/whānau support needs, further assessment and referrals, and
- sources of further information or support.

6 What can you do to help?

It may take considerable time for the person to be seen and assessed. The person who refers them needs to ensure that they are aware of the likely timeframe.

It might be appropriate to provide them with information or referral for services such as needs assessment or other support while they are waiting for, or undergoing, diagnostic assessment (see page 12 for contact details).

After diagnosis

Where the person is a child or adolescent under 16 years of age, the information about diagnosis will be given to the family/whānau.

If the person is an adult, they can choose to take a support person and decide whether their family/whānau is informed. Usually the diagnostic team will ask them about their preferences in advance.

Sometimes it is not possible for a diagnosis to be made. In that case, the team will usually recommend a plan of action to resolve this or make recommendations based on their findings.

Usually people will be given a written summary and a copy of any report as well as information about ASD as part of the diagnosis. The amount and complex nature of the information means that people often get overloaded and forget much of what is said to them verbally. It may be helpful for people working with the person to go over the written information provided at diagnosis at a later time so that the person can better understand and be able to ask questions.

Being diagnosed as having ASD, and learning about what this means, is often very challenging for a person and their family/whānau. They may experience doubt about the diagnosis or even fear, despair, anger and/or depression. Some people find a diagnosis of ASD a relief, making sense of what may have been years of difficulty.

Regardless of their reaction, the person and their family/whānau will need support to:

- source further counselling from appropriately-skilled practitioners
- access quality information and parent education (if appropriate)
- access appropriate resources, support and assistance
- network with other people with ASD and their families/whānau
- identify appropriate educational options and placements
- identify supports for family/whānau, such as respite, home support and behaviour support
- access appropriate treatment for any comorbid disorders.

7 Resources for further information

This resource has been developed by the New Zealand Guidelines Group, with funding from the Ministries of Health and Education and is one of three resources available online at www.nzgg.org.nz/asd The full set of resources and their purpose is:

- **‘What does ASD look like?’**
  A resource to help people in education, health and community settings identify signs that may indicate ASD, and decide what action to take.
- **‘Does this person have ASD?’**
  A resource for the professionals who will make an initial assessment and then may refer the person on for specialist diagnosis.
- **‘How is ASD diagnosed?’**
  An introduction to diagnosis of autism spectrum disorder to help people understand the process and steps in a formal diagnosis.

Further evidence-based information on ASD is available from Altogether Autism, Autism New Zealand and the Ministry of Education. These agencies provide ASD information and advice to people with ASD, their parents and families/whānau, professionals, service providers and the wider community.

Altogether Autism

0800 ASD INFO (0800 273 463)
info@altogetherautism.org.nz
www.altogetherautism.org.nz

Autism New Zealand

0800 AUTISM (0800 288 476)
info@autismnz.org.nz
www.autismnz.org.nz

Ministry of Education

0800 622 222
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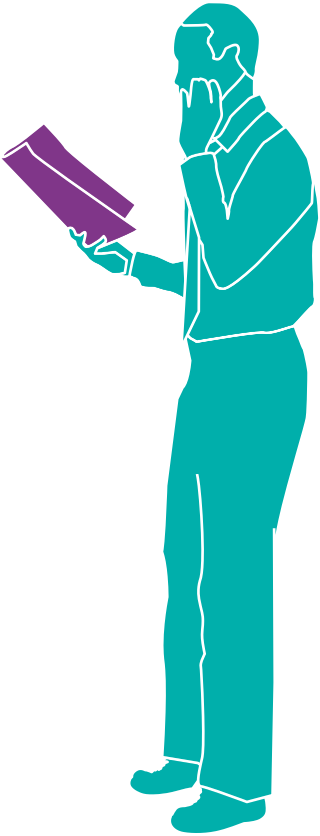

8 Acknowledgements

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