

Does this person have ASD?

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.



Contents

1	Who is this for?	page 1
2	What is autism spectrum disorder (ASD)?	page 2
3	What are signs of possible ASD?	page 6
4	What should I do if I suspect ASD?	page 9
5	Some pointers for conducting an assessment	page 11
6	Associated conditions	page 13
7	How can I support people going through the assessment process?	page 14
8	Why is diagnosis important?	page 15
9	How to make a referral	page 17
10	Notes for general practitioners	page 19
11	The ASD referral process	page 21
12	Appendix: Key signs for identifying ASD from the NZ ASD Guideline	page 23
13	Resources for further information	page 29
14	Acknowledgements	page 31

1 Who is this for?

This resource is for health and education practitioners who make initial clinical assessments for ASD, and refer for specialist hospital assessment, if needed. Referrers may be doctors (usually GPs), Plunket or public health nurses, Resource Teachers: Learning and Behaviour (RTLBs), speech-language therapists or psychologists.

It contains information on the basic signs and symptoms of ASD, and how to refer people for formal diagnosis when you suspect ASD.

Companion booklets in this series are:

- 'What does ASD look like?'
- 'How is ASD diagnosed?'

See page 29 for further information. There is some overlap of information in these resources.



2 What is autism spectrum disorder?

Autism spectrum disorder refers to the pervasive developmental disorders that include autism and Asperger syndrome, as well as some other disorders with similar features.

People who have ASD show difficulties in **all three** of the following areas:

1. understanding and using verbal and non-verbal communication
2. understanding social behaviour, which affects their ability to interact with other people
3. thinking and behaving flexibly, which may be shown in restricted, obsessional or repetitive activities or interests.

These difficulties are sometimes referred to as the 'triad of impairments'.

There is also a group of people who have significant difficulties in one or two of these areas, but who may not meet the criteria for an ASD.

As the term 'spectrum' implies, ASD includes a wide range of severity and is seen in people of any intellectual ability. ASD can range from some profound impairments (seen in classical or Kanner-type autism) to high-functioning autism and Asperger syndrome (where people can show remarkable talent or ability).

ASD is a developmental disorder. Presentation will vary with age and, in any one individual, will vary over time. The characteristics of ASD may be more prominent at some ages than others. There are three more common times when individuals are likely to present:

1. between the ages of 1 and 3 years, lack of development in the areas affected by ASD, such as language and play, becomes more obvious
2. between the ages of 5 and 8 years, when increased social and educational demands highlight difficulties
3. in adolescence or adulthood, when social isolation or relationship difficulties result in depression and other comorbid conditions.

Despite a large number of promising research studies, the causes of ASD are not known, although genetic factors are considered important. While there is no cure, a great deal is known about how to minimise the impact of the condition and some children make so much progress that their differences from the general population become negligible.

ASD is thought to affect about 1% of the population or more than 40,000 New Zealanders.

- In the greater Auckland region there are probably about 13,000 people with ASD
- In the Gisborne/East Coast region there are probably about 500 people with ASD
- In the combined Canterbury and Otago regions there are probably more than 7000 people with ASD

(Estimates based on Statistics New Zealand 2006 census data.)

Diagnostic criteria for ASD are available from the Diagnostic and Statistical Manual of Mental Disorders (4th edition, text revision) and the International Classification of Diseases (10th version), or see Appendix 4 (page 286) of the New Zealand Autism Spectrum Disorder Guideline (NZ ASD Guideline).

“My son struggles to communicate.”



3 What are signs of possible ASD?

You might observe (or a parent or others might describe) a child or adult who:

Young children (pre-school)	School-aged children and adults
Communication	
<ul style="list-style-type: none">• Finds it hard to communicate what s/he wants• Has language skills that are behind other children of their age• May appear to not understand what people want or say• Uses language in an unusual way (such as repeating words or songs)• Sometimes appears not to hear• Uses objects, such as a cup or DVD, or leads by the hand to show what s/he wants• Seems very independent for their age (will not seek help from others)• Has difficulty following directions	<ul style="list-style-type: none">• Finds it hard to communicate what s/he wants• Uses an unusual tone or pitch or accent (very pedantic, a monotone or an unusual accent)• May appear to not understand what people want or say• Might say 'you' or 's/he' rather than 'I' (or vice versa)• Is unaware of non-verbal communication like facial expression, body language or gesture• Takes information or instructions 'literally'• Has difficulty with new instructions or settings

Young children (pre-school)	School-aged children and adults
Social interaction or play	
<ul style="list-style-type: none"> • Prefers to play or be alone • Does not smile when smiled at • Ignores greetings and farewells (such as waving hello or goodbye) • Appears disinterested in other children or people • Does not respond when you play peek-a-boo or hide and seek games • Never plays pretend or 'make believe' (talking on the phone or looking after a doll) • Rarely bring toys and objects to share or show adults or other children • Rarely attracts other people's attention to what s/he is doing 	<ul style="list-style-type: none"> • Prefers to spend time alone • Has difficulty knowing if someone is joking • Does not follow the usual social rules for 'polite' behaviour • Has difficulty taking part in a two-way conversation • Does not readily engage in role-play or joking around • Sometimes has acquaintances, but very few friends • Sometimes says or does things that are tactless or socially inappropriate

Young children (pre-school)	School-aged children and adults
Cognition or restrictive or repetitive behaviour	
<ul style="list-style-type: none"> • Has very set and/ or unusual rituals or routines and can get very upset at changes in routine • Likes to line things up or put things in a certain order • Seems to get stuck doing the same thing over and over • Has unusual movement patterns (such as hand flapping or walking on toes) • Plays with toys in unusual ways (such as spinning the wheels on a car) • Makes unusual movements near his/her face • Shows attachments to unusual objects (such as a keyring or piece of string) • Over-reacts to loud noises (puts hands over ears) or is very sensitive to particular smells, tastes or textures 	<ul style="list-style-type: none"> • Has very set and/ or unusual rituals or routines and can get very upset at changes in routine • Likes to line things up or put things in a certain order • Has a particular interest which s/he likes to talk about and takes up a lot of time • Will recite facts about their particular interest without consideration for the listener • Has poor coordination or motor skills • Over-reacts to loud noises or is very sensitive to particular smells, tastes or textures

Note: See Appendix page 23 for signs identifying possible ASD in specific age groups.

4 What should I do if I suspect ASD?

Many studies document that parental concerns about developmental delays in their children are typically well-founded. It is not helpful, and can be potentially harmful, to tell parents not to worry or to wait and see.

A significant number of people reach adulthood without being assessed for ASD. They have often developed additional problems as a result of previous experiences and may have received the wrong type of treatment. Often, it is these additional problems that bring them to attention.

The process for assessment (see [The ASD Referral Process](#)):

- Make an initial assessment to confirm the possible presence of ASD; or to rule it out. Screening tools, which can sometimes be helpful and can be completed by parents and adults, include:
 - for young children:
the [Checklist for Autism in Toddlers](#) (CHAT)
 - for children aged 5–11 years:
[Childhood Asperger Syndrome Test](#) (CAST)
 - for adolescents and adults:
[Social Communication Questionnaire](#) (SCQ) – previously known as the ‘Autism Spectrum Disorder Screening Adults Questionnaire’.
(Note: This tool is only available for purchase.)

- Where ASD is suspected:
 - make a referral for full diagnostic assessment, providing comprehensive referral information (see [Information for a referral](#) on page 17).
- Where you are not sure:
 - seek further guidance or assessment from another professional with expertise in assessing ASD:
 - » for a child or adolescent this might be a speech-language therapist, paediatrician (ideally a specialist developmental paediatrician) or child and adolescent mental health service
 - » for an adult, this might be a psychologist or adult mental health service.
- If you feel confident you can rule ASD out:
 - you should consider referral to the appropriate service for any particular problems relating to development of communication, motor skills, or vision or hearing.

For further information, see the information on associated conditions ([page 13](#)) and notes for general practitioners ([page 19](#)).

You should only refer for further assessment if you have the informed consent of the person and their family/whānau. If you work in the education sector, this consent needs to be in writing. Information about the diagnostic process and what to expect is included in a third resource in this series:

[How is ASD diagnosed?](#) (See page 7 for details).

5 Some pointers for conducting an assessment

New routines, people and places all provide a significant challenge for people with ASD. Here are some things that you can do to help minimise anxiety during the assessment process.

- Unfamiliar busy environments, such as waiting rooms, can be challenging for people with ASD. A quiet place to wait can help to reduce anxiety.
- Some people may have no verbal communication. Others may appear quite articulate, but their communication difficulties might become more apparent over time. You may need additional time or a further appointment.
- It can be helpful to outline at the start what the consultation will involve.
- People with ASD find processing verbal language challenging and often also have difficulty interpreting body language, such as gesture and facial expression. Using visuals, such as photographs, diagrams or written material can be helpful to aid comprehension.
- It is helpful if someone who knows the child or person well can accompany them to 'interpret' and help with understanding. Ask parents or carers about approaches or communication strategies which are helpful.

“It is common for me and other people with autism to be unable to say the words to describe what is bothering us. It’s also hard for us to figure out that other people don’t experience the world the same way we do.”



6 Associated conditions

There are other conditions which can be associated with ASD and need to be considered as associated or possible comorbid conditions. These include:

- attention deficit hyperactivity disorder (ADHD)
- affective disorders
- depression
- Down syndrome
- dyslexia/dyspraxia
- epilepsy
- foetal alcohol spectrum disorder
- Fragile X
- intellectual disabilities
- learning disabilities
- nutritional deficiencies secondary to a restricted diet
- obsessive-compulsive disorders
- Rett syndrome
- schizophrenia
- sensory difficulties
- sleep difficulties
- stress and anxiety disorders
- substance abuse
- tuberose sclerosis.

This list is drawn from the NZ ASD Guideline (pages 55–56).

7 How can I support people going through the assessment process?

There is research that shows that those who support people with ASD experience very high levels of stress – even compared to those who support people with other significant disabilities.

The practical referral for diagnosis is insufficient. In addition:

- families and supporters need information about ASD
- families and supporters need referral to agencies that can offer financial support, respite and assistance with interventions even without a diagnosis
- the values, knowledge, preferences and cultural perspectives of the individual and their family need to be respected through the assessment and diagnostic processes. It is important to understand that some cultural groups have differing views about disability. Consider whether you can support the person or their family with a referral to a culturally-appropriate support service.

8 Why is diagnosis important?

Research shows that early diagnosis and interventions are more likely to result in positive effects on later skills. But no matter what the age at diagnosis, it is never too late to benefit from well-designed strategies and interventions.

Benefits of assessment and diagnosis can include:

- quality information
- parent education
- access to appropriate resources, support and assistance
- assistance with identification of appropriate educational options and placements
- assistance in the identification of supports for family and whānau, such as respite, home support and behaviour support
- help for other people to understand and support the person and their family and whānau
- consideration when seeking benefits, employment or assistance in legal matters
- for people with ASD, possible help to understand themselves and make contact with other people or support groups

- prevention of misdiagnosis
- appropriate treatment for some associated comorbid disorders such as depression and anxiety
- possible identification of the broader phenotype of ASD in family members.



9 How to make a referral

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

- psychologists, 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 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 30](#) for contact details) for information about private services.

Information for a referral

As well as details such as name and address, a referral for diagnosis of suspected ASD should include all of the following information:

- date of birth
- a National Health Index number (if known)

- ethnicity*
- observed or reported signs (including any suspicion of ASD and history of the onset of signs)
- known or suspected medical, developmental or mental health conditions
- current medication
- names, roles and contact details of people who should be informed or consulted
- residential, educational and occupational circumstances
- urgency of referral with details of any current crises or other stressors
- notes about the information you have provided on Altogether Autism, Autism New Zealand, or local Needs Assessment and Service Coordination (NASC) agencies, as appropriate
- details of any other referral you have made (eg, hearing tests, early intervention service).

Some specialist diagnostic services have referral forms that doctors need to use. Contact local services for this information.

* There are recommended best practices for accurately identifying a patient's or client's ethnicity in the Health and Disability sector. See <http://www.moh.govt.nz/moh.nsf/pagesns/400?Open> (Accessed 8 Dec 2009).

10 Notes for general practitioners

When the patient is a child, doctors should:

- conduct a thorough medical evaluation, screen vision, and make referrals for further investigation if concerns are raised. For example:
 - refer children to audiology, because hearing problems are an important differential diagnosis in ASD, and even mild hearing loss is important in children
 - seek clinical evidence of co-existing medical conditions, such as epilepsy (blood tests and other workup can be left to specialist services)
 - where appropriate, refer to the local NASC service.
- give the parents/guardian information about contacting early intervention or other education services at the local Ministry of Education, Special Education district office for support and intervention (these services can be accessed without a diagnosis)

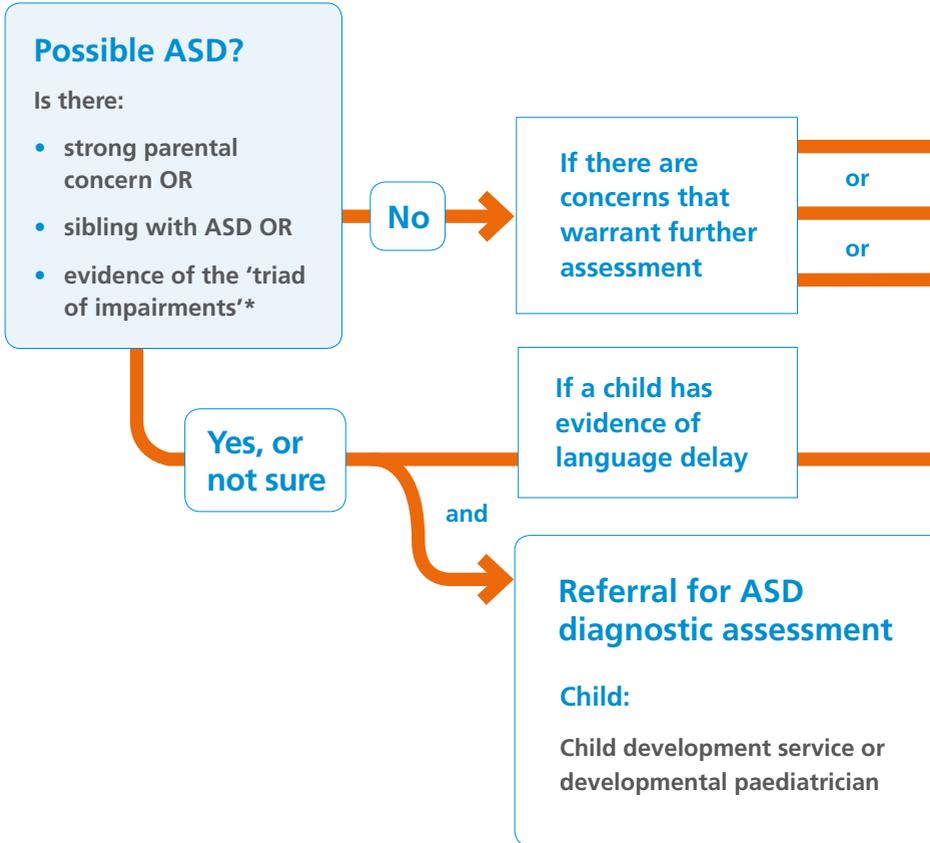


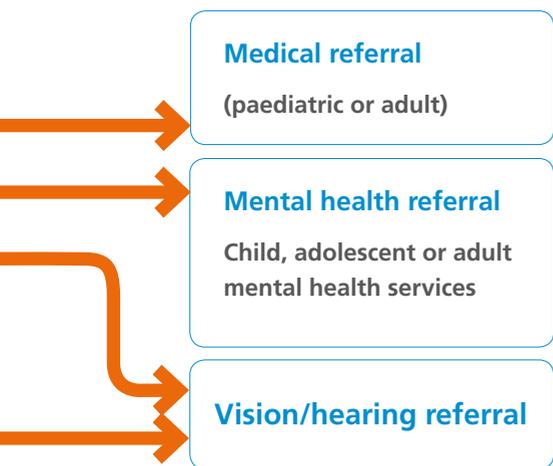
- where referral to a diagnostic service is appropriate, give the parents/guardian information about the local pathways and process for formal diagnostic services
- if parents are concerned about subtle differences in a sibling of a child diagnosed with ASD, refer the sibling for general developmental assessment or diagnostic assessment (depending on the child's age and local pathways).

When the patient is an adult, doctors should:

- obtain a history of the onset of signs of ASD during the person's childhood
- gather information (with the patient's informed consent) from people who live with or interact regularly with the person, especially regarding routines or behavioural rigidity of which the individual may not be aware
- consider the adult's mental state; mental distress is usual in an adult with undiagnosed ASD
- consider the adult's overall mental health. Mental illness can either mask or mimic ASD (eg, depression, obsessive-compulsive disorder, schizophrenia, stress and anxiety, and substance abuse) and can co-exist with ASD
- where referral to another service is appropriate, give the patient information about the local pathways and process for formal diagnostic services and/or further referral.

11 The ASD referral process





Adult:

Mental health service or private
diagnosis service

* Described in 'Signs of autism spectrum disorder', page 6.

12 Appendix

Key signs for identifying ASD in children aged 1–3 years

All children must be referred for a general developmental assessment, if they:

- do not babble, point to or show objects or make other gestures by 12 months of age
- do not say meaningful single words by 18 months of age

Social impairments

- Lack of social smile and lack of eye contact
- Lack of imitation of actions (eg, clapping)
- Deficits in joint attention, such as lack of showing, lack of shared interest, or lack of involving others in joint play with toys or other objects
- Lack of interest in other children or odd approaches to other children
- Minimal recognition or responsiveness to another's happiness or distress
- Not wanting to be picked up and cuddled
- Odd relationships with adults (either too friendly or distant)
- Limited variety of imaginative play
- Lack of pretend play, especially involving social imagination (ie, not joining with others in shared imaginary games)
- Appearing to be 'in his/her own world'
- Failure to initiate simple play with others or participate in early social games
- Preference for solitary play activities

- do not say two-word spontaneous (non-echoed or imitated) phrases by 24 months of age, or
- show a loss of any language or social skills at any age.

Communication impairments

- Impairment in language development, especially comprehension
- Unusual use of language
- Poor response to name
- Deficient non-verbal communication (eg, lack of pointing and difficulty following the pointing of others)
- Failure to smile socially to share enjoyment and respond to the smiling of others
- Abnormalities in language development, including muteness, odd or inappropriate intonation patterns, persistent echolalia, reference to self as 'you' or 'she/he' beyond 3 years, unusual vocabulary for child's age or social group
- Limited use of language for communication and/or tendency to talk freely only about specific topics



Impairment of interests, activities and other behaviours

- Over-liking for sameness and/or inability to cope with changes especially in unstructured setting
- Repetitive play with toys (eg, lining up objects or turning light switches on and off, regardless of scolding)
- Over-attentiveness to small visual details (eg, fascination with spinning wheels)
- Repetitive motor mannerisms
- Lack of flexible, co-operative imaginative play or creativity (although certain imaginary scenarios, such as those copied from videos or cartoons may be frequently re-enacted alone)
- Difficulty in organising self in relation to unstructured space (eg, hugging the perimeter of playgrounds, halls)

Key signs for identifying ASD in children aged 4–8 years

Social impairments

- Inability to join in with the play of other children, or inappropriate attempts at joint play (may manifest as aggressive or disruptive behaviour)
- Lack of awareness of classroom 'norms' (criticising teachers; overt unwillingness to co-operate in classroom activities; inability to appreciate/follow current trends, eg, with regard to other children's dress, style of speech and interests)
- Easily overwhelmed by social and other stimulation
- Failure to relate normally to adults (too intense or no relationship)
- Showing extreme reactions to invasion of personal space and extreme resistance to being 'hurried'

Other factors that may support a diagnosis of ASD

Over- or under-sensitivity to:

- sound (eg, has trouble keeping on task with background noise, responds negatively to unexpected or loud noises)
- touch (eg, discomfort during grooming, avoids getting messy, picky eater, especially regarding certain textures)
- movement (eg, becomes anxious or distressed when their feet leave the ground, or twirls, spins, or rocks self frequently during the day)
- visual stimuli (eg, prefers to be in the dark, feels discomfort or avoids bright lights)
- smells (eg, seeks out certain smells).



Communication impairments

- Abnormalities in language development, including muteness, odd or inappropriate intonation patterns, persistent echolalia, reference to self as 'you' or 'she/he' beyond 3 years, unusual vocabulary for child's age or social group
- Limited use of language for communication and/or tendency to talk freely only about specific topics

Impairment of interests, activities and other behaviours

- Lack of flexible, co-operative imaginative play/creativity (although certain imaginary scenarios, for example, copied from videos or cartoons, may be frequently re-enacted alone)
- Difficulty in organising self in relation to unstructured space (eg, hugging the perimeter of playgrounds or halls)
- Inability to cope with change or unstructured situations, even ones that other children enjoy (such as school trips or teachers being away)
- Preoccupation with restricted patterns of interest that are abnormal either in intensity or focus; over-attention to parts of objects

Key signs for identifying ASD in children aged over 9 years

Young people and adults

Four factors that commonly prompt initial referral for diagnosis of people beyond childhood include:

- symptom changes and diagnostic dilemmas – where children formerly diagnosed with conditions such as PDD-NOS have matured, their behavioural and emotional characteristics have altered, and, consequently, the original diagnosis is being re-evaluated
- social deficits – where the differences in social behaviour between the person in question and same-age peers has become more obvious
- difficulty meeting academic expectations – where the person's response to the increasing demands of the educational system is of concern

Source: Ministries of Health and Education. New Zealand Autism Spectrum Disorder Guideline. Wellington: Ministry of Health; 2008 (pages 39–42).

Other factors that may support a diagnosis of ASD

- Unusual profile of skills/deficits (eg, social and motor skills very poorly developed, whilst general knowledge, reading or vocabulary skills are well above chronological/mental age)
- Any other evidence of odd behaviours, including over- or under-sensitivity to sound (eg, has trouble functioning when there is noise around), touch (eg, difficulties standing in line or close to others, avoids getting messy, or excessively touches people and objects), movement (eg, avoids playground equipment or moving toys, or seeks all kind of movement, and this interferes with daily routines), visual stimuli (eg, prefers to be in the dark, discomfort or avoids bright lights) or smells (eg, deliberately smells objects)
- Unusual responses to movement (eg, toe walking and hand flapping)
- Unusual responses to pain
- Any significant history of loss of skills

- considerations such as family, cultural, community, or other demographic factors that mediate the dysfunctional quality of behaviours – where factors formerly suspected to account for the child's behavioural characteristics hold less weight.

Similar factors may well initiate referrals for diagnosis in high-functioning adolescents and adults (ie, those who could be diagnosed with high-functioning autism (HFA) or Asperger syndrome (AS)). Differences in behaviour and emotional understanding may become more obvious as people move into the demands of the adult world of higher education, employment, independence and intimacy.

13 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

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