

What does ASD look like?

New Zealand Autism Spectrum Disorder Guideline



A resource
to help identify
autism spectrum
disorder

Citation: New Zealand Guidelines Group. 2010. What does ASD look like? A resource to help identify autism spectrum disorder. Wellington: New Zealand Guidelines Group.

ISBN: (electronic): 978-1-877509-20-9

HP5010

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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1 Who is this for?

This resource is for people who might come across adults or children who might have an autism spectrum disorder (ASD).

It is to help you identify signs that may indicate ASD and help you decide what actions you can take. Some people who may find it useful include those:

- working in education settings such as schools, early childhood centres and tertiary institutions
- working in health and disability services such as child health, primary care, youth health, hospital and community services, or counselling services
- in government services such as social welfare, police, legal and court services
- in community settings such as relatives, friends, caregivers, co-workers, sport and interest groups, social service or accommodation providers.

It is also for those of you who have come across people who are concerned that someone they know might have ASD. Finally, it is also for those of you who suspect that you might have ASD yourself.

Companion resources in this series are:

- 'Does this person have ASD?'
- 'How is ASD diagnosed?'

2 What is ASD?

As a person grows from birth to adulthood, there are a number of milestones in cognitive development (brain or intellect), social development (which includes play) and in the development of communication (language) skills that he or she will usually reach.

While many people have some delay in development of one or other of these areas, ASD is the name for a group of conditions where a person has delay or difficulty in **all three** of these areas. These difficulties vary with a person's age, but people with ASD generally have trouble:

1. understanding and using verbal (language) and non-verbal (facial expression, gesture and body language) communication
2. understanding social behaviour, which affects their ability to play or interact with other people
3. thinking and behaving flexibly, which may be shown in restricted, obsessional or repetitive activities.

Common times in a person's life when ASD is more likely to be noticed are:

- between the ages of 1 and 3 years, when a lack of development in the areas affected by ASD such as language and play, becomes more obvious
- between the ages of 5 and 8 years, when increased social and educational demands can highlight difficulties
- in adolescence or adulthood, when people with ASD can feel socially isolated or may have relationship difficulties that result in depression or other mental health problems.

Each person with ASD will be unique because:

- some will have serious problems in each area
- others will have mild problems in all areas
- some might have more difficulty in one or two areas
- of individual factors such as personality
- of family settings, circumstances and culture
- of different levels of intellectual ability.

Many people with ASD have impressive strengths and abilities that are directly related to their ASD (eg, an exceptional honesty and reliability, ability to focus on a detailed task, punctuality and adherence to rules, and a drive for perfection and order). These traits can also be present in people without ASD.

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 are based on Statistics New Zealand 2006 census data.)

The cause of ASD is not known, although genetic factors are considered important. A great deal is known about how to minimise the impact of the condition. Some children make so much progress that their differences from the general population become negligible.

“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.”



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, or using overly formal or academic language)• 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 • Difficulty initiating or sustaining eye contact • 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 restricted 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

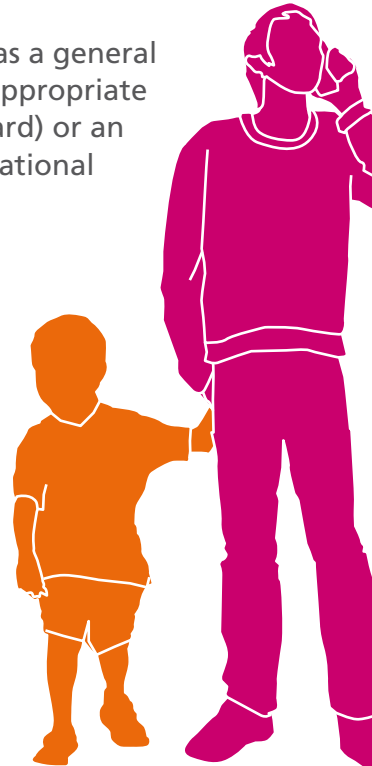
Note: See Appendix page 19 for signs identifying possible ASD in specific age groups.

4 What should I do if I suspect ASD?

If you suspect someone might have ASD after reading about the signs, the next step is to advise and support the person and/or their family/whānau to go to someone who can further assess and, if appropriate, refer for diagnosis.

This might be a health practitioner (such as a general practitioner, clinical psychologist, or the appropriate service if you work in a district health board) or an educational professional (such as an educational psychologist, speech-language therapist or a Resource Teacher: Learning and Behaviour).

If you have concerns, you need to have a well-considered plan of action, as raising the possibility of ASD can be devastating for individuals and/or their family/whānau.



If you are not confident, you should ask for the support of someone more experienced to help, guide or work out a plan for you. You could share your concerns about the person's behaviours with a senior colleague or talk to someone who is knowledgeable about ASD.

A good plan will ensure that you:

- have considered the possible reaction of the person or their family/whānau
- can raise the issue in a way that they will be able to accept
- will be able to guide and support them to access further help
- understand that some cultural groups have differing views about disability and you need to consider this in your planning.

Some people may not wish or be ready to take the next steps towards assessment and/or diagnosis.

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.

5 What might happen next?

The process for diagnosis depends on the services available in your local area. The professional who makes the referral should be able to explain the process, any waiting times and what it will entail. More information about the process for diagnosis is included in a companion resource in this series: [‘How is ASD diagnosed?’](#)

If your concerns are accepted by a health or education professional, then she or he will do some assessments and/or screening tests before deciding whether or not to refer the person for formal diagnosis.

The diagnosis itself will be made by professionals who are experienced in this area. Some people who appear to have these difficulties might not be assessed as having serious enough difficulties for a diagnosis to be made. Sometimes the difficulties might be better accounted for by another condition (eg, hearing impairment or ADHD*). Others might have other serious conditions and a diagnosis is important to rule this out.

The process of recognition, assessment and referral can tend to focus on the difficulties that a person has, which can be a very negative experience for them or their family/whānau. You should help them to consider the strengths and skills that the person has and support them and their family to find ways to encourage and extend these.

* Attention deficit hyperactivity disorder

When a person and their family/whānau choose to explore further assessment and possible diagnosis, they need access to support and accurate information. Information will help to find strategies to help with the individual's social, communication and cognitive difficulties (such as providing structure and predictability), which will be appropriate whether or not that person has ASD. It is easy for people to get inaccurate and confusing information from the hundreds of references available on the internet.

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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www.altogetherautism.org.nz

Autism New Zealand

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Ministry of Education

0800 622 222
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www.minedu.govt.nz/asd

6 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.

After diagnosis, families and individuals will be able to access a range of supporting resources. The exact nature of the resources depends on what is available within your town or city and you may need to travel to access them. The range of resources includes:

- information
- parent education
- professional advice and support to develop strategies that can be used at home, at school and in the community
- support to access respite, home support and other services, as appropriate
- consideration when seeking benefits, employment or assistance in legal matters
- treatment and support, if the person is receiving physical or mental health services, as appropriate.

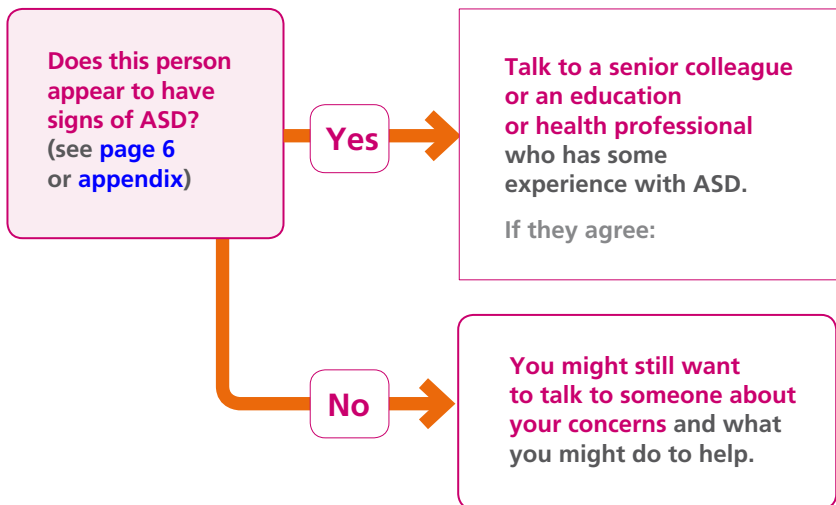
Some young people and adults with ASD will experience stress and have difficulty managing the demands of everyday life. Diagnosis, where it is sought by the individual, can help by leading to better information, understanding and support.

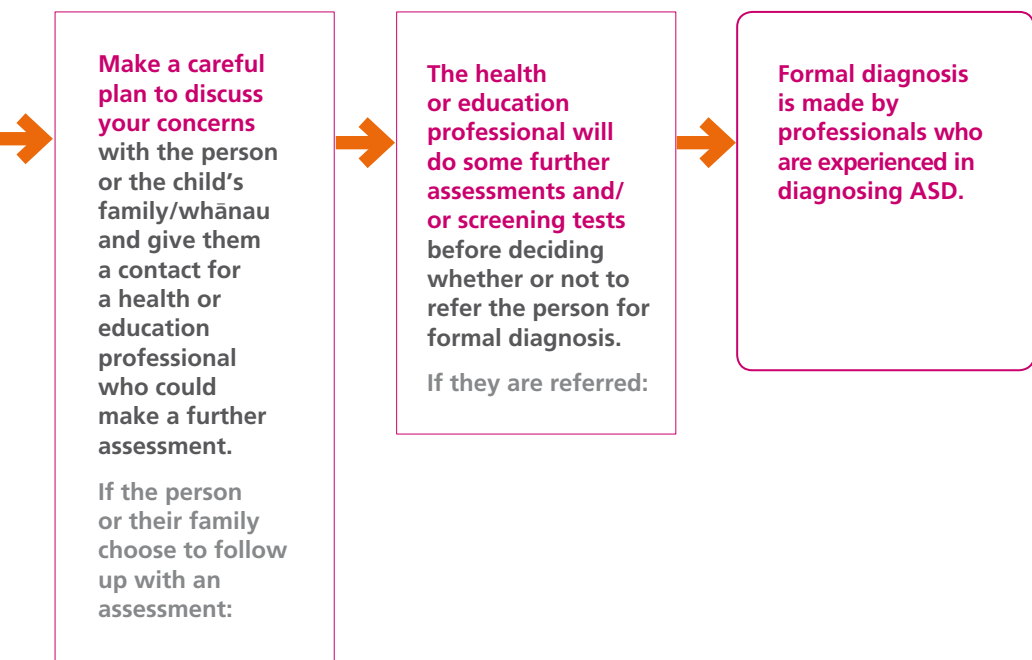


7 What is the process?

The term ASD refers to a wide range of conditions, behaviours, abilities or impairments. Judging whether someone may have ASD and deciding whether to discuss this with them and/or their family/whānau requires expertise and may involve more than one contact with the person. The process is summarised below.

The path to a diagnosis





“Many adults with autism believe that positive family involvement and support help individuals with autism develop the skills necessary to be as successful as possible as adults. I think it was the work of many people who loved me that got me where I am now...”



8 List of useful terms

Asperger syndrome: a name for one of the ASD conditions. Individuals with Asperger syndrome usually have more typical verbal and cognitive skills, and sometimes have impressive abilities in certain areas (also referred to as high-functioning autism)

Cognition: a term for the processes used in thinking

Echolalia: immediate or delayed repeating of words, noises or phrases

Gait: way of walking or running

Joint attention: sharing the experience of observing an object or event, by looking where someone else is looking or following pointing gestures with your eyes

Kanner syndrome: where a person with ASD is more severely affected in all of the relevant areas of development (also referred to as classical autism)

Pervasive developmental disorder (PDD): another term for ASD

Sensory sensitivities: very strong reactions to (either seeking or avoiding) particular sensory experiences (such as touch, sound, sight, taste, etc)

Theory of Mind: the ability to put yourself in other people's shoes to imagine their thoughts, intentions and possible actions

Triad of impairments: refers to the three core areas of development affected by ASD (communication, socialisation and cognition)

9 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

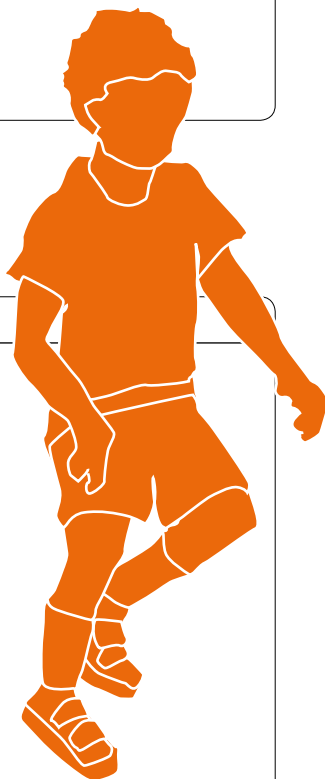
Social impairments

- 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.

10 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.

There is some overlap of information in these companion resources.

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.

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11 Acknowledgements

The New Zealand Guidelines Group wishes to thank those individuals and groups who helped to develop this material, including **Tanya Breen**, Consultant Clinical Psychologist (Hamilton), **Keryn Mells**, Technical Editor and **Te Whanau Kotahi** for their contributions.

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