

Working with People with  
**Autism Spectrum Disorder:**  
An Interim Guideline for  
Ministry of Health Needs Assessment  
and Service Co-ordination Organisations



23-4-08  
Name: Daniel Phillips  
Title: A yellow cup and  
a green cup and a  
blue cup makes 3 cups.  
Medium: Oil Pastel.

Cover artwork by Daniel Philips who is a person with autism. Daniel works at the Petone Arthouse and has many exhibitions of his work in the Wellington area.

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# About this NASC ASD Guideline

## 1. Purpose

Working with People with Autism Spectrum Disorder: A Guideline for Ministry of Health Needs Assessment and Service Co-ordination Organisations (also known as the NASC ASD Guideline) has been developed as a guide to support delivery of appropriate and consistent needs assessment and service co-ordination services for people with autism spectrum disorders (ASD).

## 2. Audience

This document is for Needs Assessment and Service Co-ordination (NASC) organisations contracted by the Ministry of Health, including Regional Intellectual Disability Care Agencies (RIDCA). It is intended for use by:

- NASC managers
- assessment facilitators
- service co-ordinators, intensive service co-ordinators and care co-ordinators.

## 3. Practice implications

Practice implications provide guidance to NASC organisations on their responsibilities when working with people with ASD. These implications appear in a box after relevant subsections. A complete set of practice implications is included in Appendix 1.

## 4. Background

The primary role of NASC is to maximise and support the abilities of disabled people by enabling them to identify their needs and goals, and make decisions about how both of these can be met. Through NASC, the Ministry of Health provides support to access a range of funded and unfunded services. Improved awareness of ASD, earlier diagnosis and rising public expectations have resulted in an increasing number of referrals of children, young people and adults with ASD to NASC. Some of these people have very complex support needs.

In April 2008 the New Zealand Autism Spectrum Disorder (NZ ASD) Guideline (NZ ASD Guideline 2008) was released. That guideline covers the identification and diagnosis of ASD, ongoing assessment, and access to interventions and services for individuals with ASD. It seeks to provide the best evidence currently available to assist informed decision-making undertaken with the aim of improving the health, educational and social outcomes for individuals with ASD and where appropriate their families, carers, whānau and aiga. The New Zealand Autism Spectrum Disorder Guideline is the key reference for the NASC ASD Guideline, which follows the content of and the terms within the NZ ASD Guideline.

#### Practice implication

1. All staff will be aware of the NZ ASD Guideline, and designated staff will be familiar with and competent in handling ASD-related cases.

## 5. Currency and related documents

The NASC ASD Guideline is based on systems, services and Ministry of Health policies in place at the time of writing (June to September 2009). These will change over time in response to policy developments and as key recommendations of the NZ ASD Guideline are considered and implemented. Further work to support and implement the NZ ASD Guideline (the 'living guideline' process) is underway. This work will alter the information and evidence upon which the NASC ASD Guideline is based. Documents that informed the development of the NASC ASD Guideline are listed in Appendix 2.

The NASC ASD Guideline will be updated to reflect the outcomes of work currently underway on health and disability support sector responsibilities.

#### Practice implications

2. Review Working with People with Autism Spectrum Disorder: A Guideline for Ministry of Health Needs Assessment and Service Co-ordination Organisations, and update it according to changes in systems, services, policies, and the information on and evidence base of ASD.
3. NASC organisations hold together in one reference package: the New Zealand Autism Spectrum Disorder Guideline; Working with People with Autism Spectrum Disorder: A Guideline for Ministry of Health Needs Assessment and Service Co-ordination Organisations; current Ministry of Health policy documents; and all relevant ASD documents developed as part of the process of implementing the New Zealand Autism Spectrum Disorder Guideline.

## 6. Acknowledgements

The New Zealand Needs Assessment Service Co-ordination Association (NASCA) was contracted by the Ministry of Health to develop the NASC ASD Guideline. NASCA engaged Tanya Breen, consultant clinical psychologist (Hamilton), to develop the NASC ASD Guideline. Also integral to the development of this document and engaged by NASCA were Sandra Murray (overall project manager) and Pip Nicholls and Henry Harrison (project managers for related work).

Consultation undertaken involved NASC managers, consumers, NASC staff, and officials from the Ministries of Health and Education. See Appendix 3 for details of the people consulted.

# Information and Practice Implications

## 1. Definition of autism spectrum disorder

Autism spectrum disorder (ASD) refers to the group of pervasive developmental disorders that includes autism and Asperger syndrome, as well as disorders with similar features that do not fit into these diagnostic categories (for more information, see NZ ASD Guideline 2008).

ASD covers a wide range of severity and intellectual ability, from the severe impairment seen in classical autism to a 'high functioning' individual with Asperger syndrome.

## 2. Core deficits

The 'core deficits' of ASD (also known as the 'triad of impairments'), which people diagnosed with ASD all display, are:

- impairment in the ability to understand and use verbal and non-verbal communication
- impairment in the ability to understand social behaviour, which affects their ability to interact with other people
- impairment in the ability to think and behave flexibly which may be shown in restricted, obsessional or repetitive activities.

These features of ASD affect the individual's functioning in many (sometimes all) areas, although intensity may vary depending on the context and the person's emotional state. As ASD is a developmental disorder the presentation will vary with age and, in any one individual, vary over time.

Due to the core deficits of ASD, people with ASD generally have significant problems in several of the following areas (NZ ASD Guideline 2009, pp 34–59, 286–288).

- In regard to **communication** there can be:
  - absence of, or delay in developing, verbal language
  - peculiar use of language, tone or voice
  - poor understanding of common phrases
  - literal interpretation of language, and misinterpretation of 'sayings'
  - poor understanding of body language.
- In regard to **social understanding** there can be:
  - lack of, or significantly lowered, interest in interacting with others
  - inability, or impaired ability, to interact with people (especially peers)
  - difficulty with making and maintaining friends

- misunderstanding of social rules, conventions, cues and/or hints
  - inappropriate behaviour in a variety of social situations
  - a limited range of emotional expression, and frequently a lack of subtle expression of emotion
  - poor use and understanding of facial gestures
  - lack of, or lowered, demonstration of concern for others (empathy)
  - impaired sharing of interests or activities with others
  - lack of spontaneous behaviour seeking to share enjoyment.
- In regard to **behavioural flexibility** there can be:
    - difficulty with changing from one activity to another, dealing with changes in routine or being interrupted
    - difficulty with coping with new people, different environments and changed expectations
    - strong adherence to specific rules, rituals or routines
    - tendency to be extremely interested in or fixed on a very small number of activities or objects, rather than engaging in a wide range of activities
    - collection of objects and/or facts, and strong interest in factual information rather than fiction.

Other possible concerns include: clumsiness; unusual gait when running; unusual sensitivity to noise, touch, taste, texture or sound; tendency to flap or rock; and an unusual pain response.

### 3. Strengths

Many people with ASD have strengths directly related to the characteristics of ASD (eg, exceptional ability to focus on one task, punctuality, rule adherence, seeking perfection and order). Although the person's support needs within the contexts of home, family and community support needs are the focus of a NASC assessment, it is also important to consider the person with ASD from a 'strengths' perspective.

### 4. Recognition of ASD at different ages

It is important to recognise signs of ASD in childhood, which can lead to diagnostic assessment. For useful information, see Tables 1 and 2 below.

Recognition and diagnosis of ASD in later childhood, adolescence and adulthood is also based on the three core deficits (described above). Diagnosis in adulthood is complicated by the need for a history of the presence of these difficulties in childhood, and by the potential for a number of mental illnesses to mask or mimic ASD.

#### Practice implications

4. Understand the term 'autism spectrum disorder' and recognise the wide range of presentations.
5. Recognise the core deficits associated with ASD.
6. Recognise signs of ASD in children, young people and adults.

**Table 1: Key signs\* for identification of children with ASD 1–3 years**

All children with ANY of the following findings MUST be referred for a general developmental assessment	
<ul style="list-style-type: none"> <li>• no babble, pointing to or showing of objects or other gesture by 12 months</li> <li>• no meaningful single words by 18 months</li> <li>• no two-word spontaneous (non-echoed or imitated) phrases by 24 months</li> <li>• ANY loss of any language or social skills at ANY age.</li> </ul>	
Social impairments	Communication impairments
<ul style="list-style-type: none"> <li>• lack of social smile and lack of eye contact</li> <li>• lack of imitation of actions (eg, clapping)</li> <li>• 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</li> <li>• lack of interest in other children or odd approaches to other children</li> <li>• minimal recognition or responsiveness to another’s happiness or distress</li> <li>• not wanting to be picked up and cuddled</li> <li>• odd relationships with adults (either too friendly or distant)</li> <li>• limited variety of imaginative play</li> <li>• lack of pretend play, especially involving social imagination (ie, not joining with others in shared imaginary games)</li> <li>• appearing to be ‘in his/her own world’</li> <li>• failure to initiate simple play with others or participate in early social games</li> <li>• preference for solitary play activities.</li> </ul>	<ul style="list-style-type: none"> <li>• impairment in language development, especially comprehension</li> <li>• unusual use of language</li> <li>• poor response to name</li> <li>• deficient non-verbal communication (eg, lack of pointing and difficulty following the pointing of others)</li> <li>• failure to smile socially to share enjoyment and respond to the smiling of others</li> <li>• abnormalities in language development, including muteness, odd or inappropriate intonation patterns, persistent echolalia, reference to self as ‘you’ or ‘she/he’ beyond three years, unusual vocabulary for child’s age/ social group</li> <li>• limited use of language for communication and/or tendency to talk freely only about specific topics.</li> </ul>

Impairment of interests, activities and other behaviours	Over- or under-sensitivity to
<ul style="list-style-type: none"> <li>• over-liking for sameness and /or inability to cope with changes especially in unstructured setting</li> <li>• repetitive play with toys (eg, lining up objects or turning light switches on and off, regardless of scolding)</li> <li>• over-attentiveness to small visual details (eg, fascination with spinning wheels)</li> <li>• repetitive motor mannerisms</li> <li>• 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)</li> <li>• difficulty in organising self in relation to unstructured space (eg, hugging the perimeter of playgrounds, halls).</li> </ul>	<ul style="list-style-type: none"> <li>• sound (eg, has trouble keeping on task with background noise, responds negatively to unexpected /loud noises)</li> <li>• touch (eg, discomfort during grooming, avoids getting messy, picky eater especially regarding certain textures)</li> <li>• movement (eg, becomes anxious or distressed when feet leave the ground, or twirls/spins/rocks self frequently during the day)</li> <li>• visual stimuli (eg, prefers to be in the dark, feels discomfort or avoids bright lights)</li> <li>• smells (eg, seeks out certain smells)</li> </ul>

*\* Each of these factors in isolation is not indicative of ASD. They are intended to alert professionals to the possibility of ASD. Source: Adapted from NZ ASD Guideline (2008, pp 39–40)*

**Table 2: Key signs for identification of children with ASD 4–8 years**

Communication impairments	Social impairments
<ul style="list-style-type: none"> <li>• 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/ social group</li> <li>• limited use of language for communication and/or tendency to talk freely only about specific topics.</li> </ul>	<ul style="list-style-type: none"> <li>• inability to join in with the play of other children, or inappropriate attempts at joint play (may manifest as aggressive or disruptive behaviour)</li> <li>• 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, interests)</li> <li>• easily overwhelmed by social and other stimulation</li> <li>• failure to relate normally to adults (too intense/no relationship)</li> <li>• showing extreme reactions to invasion of personal space and extreme resistance to being ‘hurried’</li> </ul>
Impairment of interests, activities and other behaviours	Other factors which may support a diagnosis of ASD
<ul style="list-style-type: none"> <li>• lack of flexible, co-operative imaginative play/creativity (although certain imaginary scenarios, eg, copied from videos or cartoons, may be frequently re-enacted alone)</li> <li>• difficulty in organising self in relation to unstructured space (eg, hugging the perimeter of playgrounds, halls)</li> <li>• inability to cope with change or unstructured situations, even ones that other children enjoy (such as school trips, teachers being away etc.)</li> <li>• preoccupation with restricted patterns of interest that are abnormal either in intensity or focus; over-attention to parts of objects.</li> </ul>	<ul style="list-style-type: none"> <li>• 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)</li> <li>• 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)</li> <li>• unusual responses to movement (eg, toe walking and hand flapping)</li> <li>• unusual responses to pain</li> <li>• any significant history of loss of skills.</li> </ul>

## 5. Prevalence

There is no information on the prevalence of ASD in New Zealand, according to the New Zealand Autism Spectrum Disorder Guideline. However, ASD is thought to affect more than 40,000 New Zealanders. Through the National NASC Information System (as of September 2009 known as 'Socrates'), NASC can collect data on ASD and, by doing so, contribute important data (eg, rates and distribution of people with ASD needing support in New Zealand, patterns of functional impairment, common co-existing conditions and associated support needs and costs).

## 6. Diagnostic assessment

When a child, young person or adult has signs and symptoms suggestive of ASD, serious difficulty managing the tasks and demands of everyday life, and their difficulties cannot be easily explained, it is appropriate to consider whether they have a developmental, emotional or mental health problem. Formalised, this process is called 'diagnostic assessment'.

Diagnosis is the identification of the condition(s) that best describes the person's problems. Diagnostic assessment considers all possible factors or conditions that might affect the person, alone or in combination. Sometimes diagnostic assessment is inconclusive, perhaps with a provisional diagnosis only, and involves a recommendation for further assessment at a later date. A

provisional diagnosis is more likely to occur when the person is very young, when their presentation is complex, or when co-existing conditions are present.

Signs of ASD in early childhood can be similar to those of other developmental problems. In recognition that early detection of all developmental difficulties is important, the Well Child/Tamariki Ora National Schedule recommends that all children with any of the following findings must be referred (through their general practitioner – GP) for a general developmental assessment:

- lack of babble, pointing, showing of objects or other gesture by 12 months
- no single meaningful words by 18 months
- no two-word spontaneous (non-echoed or imitated) phrases by 24 months
- any loss of language or social skill at any age.

## 7. NASC role in relation to recognising signs and making referral

The NASC role in diagnosis is to recognise signs of ASD (for detail, see New Zealand Guidelines Group 2009) and to consider initiating referral for diagnostic assessment. However initiating referral (for referral pathways, see New Zealand Guidelines Group 2009) must only

occur with the informed consent (Code of Health and Disability Services Consumers' Rights) of the person or their parent/caregiver. Access to publicly funded diagnostic assessment is typically through GP referral to health services. When significant concerns exist about the behaviour or mental state of a person with intellectual disability, NASC may request that the behavioural or mental health assessment also consider diagnosis and the possibility of ASD.

Referrers (eg GPs), diagnostic clinicians, and providers of various health and education services sometimes suggest to people newly diagnosed with ASD (or their families, carers, whānau and aiga) that they should contact a NASC organisation for support and assistance. Sometimes there is confusion about the NASC role and function.

### Practice implications

7. Record 'Other Autistic Spectrum Disorder (ASD)' in the National NASC Information System whenever a provisional or firm diagnosis of ASD or autism is made for a person. Record 'Asperger's Syndrome' in the National NASC Information System whenever a provisional or firm diagnosis of Asperger's is made for a person.

8. Consider initiating referral for general developmental assessment when signs of developmental delay in early childhood are recognised.

9. Obtain informed consent before initiating referral for general developmental assessment and/or diagnostic assessment.

10. Consider initiating referral for diagnostic assessment when ASD seems likely (but has not been diagnosed) once consent from the family is confirmed.

11. Request that behavioural or mental health assessments of a person with intellectual disability also consider diagnosis, and the possibility of ASD.

12. Be familiar with the processes outlined in the forthcoming Handbook for Recognition and Referral of Possible ASD (New Zealand Guidelines Group 2009).

13. Ensure that people with ASD and their families, carers, whānau and aiga, and all relevant agencies working with people with ASD (eg, Disability Information and Advisory Service, referrers, diagnostic clinicians, and other health and education services) are aware of the NASC organisation's role and processes.

## 8. Differential diagnosis

Signs and symptoms of ASD overlap with other conditions, and many conditions can occur alongside ASD. For more information, see Table 3 below. During diagnostic assessment, consideration of all possibilities is called 'differential diagnosis'. When additional diagnoses are unrecognised, people may not receive the support they require. All conditions should be recognised and attended to.

Symptoms of ASD have sometimes been attributed to other conditions that the person has, like intellectual disability. Many, but not all, people with ASD also have an intellectual disability. Estimates of the proportion of people with an intellectual disability who also have ASD have varied widely. Variance could be due to the difficulty in establishing the intellectual level of some people with ASD, as well as improved recognition of ASD symptoms in females and in people without cognitive impairment.

### Practice implications

14. Recognise that people with ASD may have additional diagnoses or conditions that may require support.
15. Identify disability support needs associated with all conditions that an eligible person has been diagnosed with.
16. Identify where shared support funding and/or service arrangements may be indicated and liaise with or refer to the appropriate services.
17. Be alert to the possibility of undiagnosed ASD in people with an intellectual disability, and refer to appropriate service (for referral pathways, see New Zealand Guidelines Group 2009).
18. Consider initiating diagnostic assessment if it seems likely that a person has more than one diagnosis or condition.

**Table 3: Other conditions that clinicians consider when making a differential diagnosis of ASD**

Disorders that may occur in association with ASD	Common co-morbid disorders	Medical conditions associated with ASD
<ul style="list-style-type: none"> <li>• Hearing impairment</li> <li>• Auditory processing disorder</li> <li>• Environmental deprivation</li> <li>• Attachment disorder</li> <li>• Specific language disorder</li> <li>• Semantic pragmatic language disorder</li> <li>• Dyspraxia</li> <li>• Intellectual disability</li> <li>• Selective mutism</li> <li>• Attention deficit hyperactivity disorder</li> <li>• Opposition defiant disorder</li> <li>• Conduct disorder in the older child</li> <li>• Abuse, trauma, neglect</li> <li>• Schizophrenia</li> <li>• Schizoid personality disorder</li> <li>• Disorders of impulse control</li> </ul>	<ul style="list-style-type: none"> <li>• Attention deficit hyperactivity disorder</li> <li>• Anxiety disorders (including obsessive-compulsive disorder)</li> <li>• Tourette syndrome</li> <li>• Depression</li> <li>• Developmental dyspraxia or developmental co-ordination disorder</li> <li>• Epilepsy</li> <li>• Nutritional deficiencies secondary to restricted diet</li> <li>• Specific learning disability or intellectual disability</li> <li>• Substance abuse</li> </ul>	<ul style="list-style-type: none"> <li>• Degenerative neurological or metabolic condition</li> <li>• Down syndrome</li> <li>• Foetal alcohol spectrum disorder</li> <li>• Fragile X</li> <li>• Rett syndrome</li> <li>• Tuberous sclerosis</li> </ul>

Source: Adapted from NZ ASD Guideline (2008, pp 55–57)

## 9. Initial support and earliest possible intervention

People with ASD typically experience significant, and often serious, impairment and can have complex support needs. Although there is no known cure, a great deal is known about how to help people with ASD. Newly diagnosed children, young people and adults with ASD often present to NASC organisations for support.

During the diagnostic process, and upon diagnosis, information is crucial for children, young people and adults with ASD, and their families, carers, whānau and aiga. Provision of information on ASD, and access to support that strengthens the family's resilience and helps it stay together (eg, carer support and respite care), are very important to long-term successful living.

As with other developmental problems, the earlier the diagnosis of ASD is made, the more impact intervention has, resulting in fewer challenging behaviours and better outcomes. Early intervention (which can start well before school age) is therefore recommended for children with ASD. The Ministry of Education (through Special Education) is the main provider of early intervention services. In addition the Ministry of Health provides early intervention through local child development centres (accessed through GP, health specialist and NASC referral).

Young people and adults with undiagnosed ASD can endure great stress, and have serious difficulty managing the tasks and demands of everyday life. They can be misunderstood, blamed, teased, bullied and poorly supported. Undiagnosed, they might miss out on effective treatment, and receive inappropriate medical, psychiatric and educational interventions. Earliest possible diagnosis of ASD assists in achieving understanding of the person's situation, more appropriate support and intervention, and better outcomes.

### Practice implications

19. Provide people with ASD, and their families, carers, whānau and aiga, with appropriate and accessible information about ASD, sources of further information on ASD, and information on the NASC organisation's role and processes.
20. Consider support, both within existing natural networks and funded services, that strengthens family resilience (eg, carer support and respite care) and that helps the family stay together.
21. Always obtain informed consent before sharing any information or making referral for services.

22. Establish if early intervention is occurring (or if referral has been initiated) for any child referred to a NASC organisation who has a provisional or confirmed diagnosis of ASD.

23. Initiate early intervention services through referral to Special Education, the GP and health specialists.

## 10. ASD Disability Information and Advisory Service

Information on ASD is available from the ASD Disability Information and Advisory Service (DIAS). ASD DIAS provides ASD information and advice to people with ASD, and the people who support them. The information can be general (eg, answering questions like, 'What is ASD?'), can be tailored to the person's particular circumstances or specific questions, or can comprise names and contact details of services available nationally and in local areas. ASD DIAS services are available to NASC organisations. See Appendix 4 for details.

### Practice implications

24. Liaise with ASD DIAS on a regular basis for information on national and local ASD service providers, and developments in ASD.

25. Provide people with ASD with contact details for ASD DIAS.

## 11. Eligibility of people with ASD

Children, young people and adults with ASD can access disability support through NASC, depending on eligibility. Not all people referred to NASC organisations will necessarily be eligible. NASC organisations determine eligibility according to current policy. A NASC organisation will follow the usual processes of consultation with designated people in the Ministry of Health if it needs to confirm the application of eligibility criteria.

Occasionally people with ASD may be determined to be eligible for a limited period, usually until diagnostic and other assessments are completed. This circumstance usually applies to very young children, whom it is difficult to assess and/or diagnose.

### Practice implications

26. Ensure that people with ASD fulfil the eligibility criteria of Disability Support Services (by screening, seeking additional information and referring to current Ministry of Health policy) before offering or arranging NASC services.

27. Apply eligibility criteria consistently and transparently within each NASC organisation.

28. Ensure that people given eligibility for a limited period are fully aware that the services they receive will be reviewed and that service provision may be temporary or time-limited, and will depend on the outcome of future assessments.

29. Regularly review and re-assess people with ASD who have eligibility for a limited period.
30. Provide information on ASD DIAS to people with ASD who are not eligible for NASC services, and refer them to alternative appropriate services (where available).
31. Follow specific Ministry of Health directions as they relate to specific situations.

## 12. Strengths, support needs and desired outcomes

The strengths, support needs and desired outcomes for people with ASD are as varied as those that exist for people everywhere. Assessment facilitation should therefore be comprehensive, yet sensitive to each person’s situation. It should consider personal strengths and resources, in addition to issues.

Consultation with consumers, NASC managers and NASC staff during the development of the NASC ASD Guideline suggested that assessment facilitators should:

- ensure that they know what ASD is, and be aware of the core signs and common issues of concern before contacting the person with ASD or their family, carers, whānau and aiga
- contact the person with ASD, and/or their family, carers, whānau and aiga, in advance

of the assessment to gather information to ensure that they are aware of and use strategies needed to ensure the physical, emotional and cultural safety of all involved

- be sensitive to the discomfort that the person with ASD, and their family, carers, whānau and aiga, may feel when a stranger comes into their home, and when they are required to discuss private and personal family matters
- recognise that focusing on needs and deficits can have a negative impact on emotional wellbeing, and ensure that strengths are also central to the assessment process
- reassure the person being assessed, and their family, carers, whānau and aiga, that identification of strengths, resources and successful strategies will facilitate rather than hinder appropriate support, and that this process is not conducted with the sole intention of reducing or removing supports (while noting that both reassessment and review processes may change or reduce support, particularly where there is a change in the person’s support needs)
- provide accurate and timely information when support needs cannot be met by existing contracts and services, in order to prevent frustration and disappointment

- in recognition of the anxiety that change can trigger and the social difficulties associated with ASD, ensure that wherever possible there is continuity of personnel when working with people with ASD and their families, carers, whānau and aiga – a continuity that extends to the same staff member having the role of both assessment facilitator and service co-ordinator
- respond sensitively, and in a timely way, to people with ASD and their families, carers, whānau and aiga when identified support needs cannot be met, or there are waiting times for services.

Practice implications
32. Be knowledgeable about ASD before making initial contact.
33. Before meeting become aware of the strategies needed to ensure the physical, emotional and cultural safety of all involved, and use these strategies on meeting.
34. Be sensitive to the discomfort that people may experience during assessment facilitation.
35. Identify natural networks and community resources.
36. Reassure people that identification of strengths, resources and successful strategies will not hinder support and is not conducted with the sole intention of removing support.

37. Provide accurate and timely information when support needs cannot be met by existing contracts and services.
38. Wherever possible, arrange for assessment facilitation and service co-ordination to be carried out by the same NASC staff member, if that is the preference of the person with ASD and their family, carers, whānau and aiga.
39. Identify the strengths and resources of a person with ASD and their family, carers, whānau and aiga.

### 13. Impact of ASD symptoms

Although there is great overlap in support needs between disabled people in general and people with ASD in particular, facilitated assessment should take into account the core deficits and issues/ conditions associated with ASD. Unrecognised and not attended to, ASD symptoms can be ‘barriers’ to support.

Difficulties with communication affect a person’s ability to:

- provide information to NASC staff and other professionals
- understand and communicate their own needs
- understand explanations and information about how to meet their own needs
- access services to meet their needs.

A person’s level of understanding of social situations, and their ability to form relationships impact on their ability to:

- form relationships with NASC staff, care workers, health and education professionals
- understand the roles of assessment facilitators and service co-ordinators, and others involved in their care and support
- behave appropriately with people, and understand the behaviour of others
- understand relationship boundaries
- trust.

These same factors influence their willingness to disclose important information.

Their degree of behavioural flexibility and strength of specific interests impact on a person’s ability to:

- meet with NASC staff and others involved in their care and support
- participate in assessments and other processes
- make changes to their daily routines or situation
- attend to matters that NASC staff and other professionals believe are important.

Under- and over-sensitivity to light, sound, touch, taste and pain can:

- complicate the person’s support needs

- lead to unpredictable reactions to everyday events, interventions and medication.

Additional diagnoses can:

- complicate the person’s support needs
- lead to difficulty with accessing appropriate support due to difficulties between organisations regarding respective responsibilities
- require several organisations to work together to assist the person with ASD and their family, carers, whānau and aiga (eg, GP, medical specialists, mental health services, Child Youth and Family).

Practice implications
40. Tailor assessment facilitation and service/ care co-ordination processes to suit the personal characteristics and needs of people with ASD.
41. Recognise the barriers to successful assessment facilitation that can arise from the symptoms of ASD, and work to overcome these barriers.
42. Form good working relationships with other organisations to enhance the services provided to people with ASD, minimise replication and inconsistency of approaches, and prevent inter-agency disputes.

## 14. ASD-specific supports, interventions and services

The information below briefly summarises key parts of the New Zealand Autism Spectrum Disorder Guideline. As noted above, all NASC staff should be familiar with the New Zealand Autism Spectrum Disorder Guideline, and refer to it routinely for more detailed information on ASD.

### 14.1 Support for individuals, families and carers

*Note: This section is based on NZ ASD Guideline (2008, pp 61–83)*

People who share their lives with people with ASD can have extensive needs, which should be considered. Parents see the provision of information on ASD as crucial. Effective educational programmes lead to improved outcomes for people with ASD and their families, carers, whānau and aiga.

The health care needs of people with ASD can be complex, and symptoms of ASD can become barriers to good health. Comprehensive medical assessment is important. Many adults with ASD require linkages and ongoing support to manage physical wellbeing and mental health.

ASD is a diverse condition, with the level of impairment, age at diagnosis, intellectual ability, personal needs and health status varying widely. Accordingly an individualised approach to service

delivery is important, and service co-ordination is paramount. The New Zealand Autism Spectrum Disorder Guideline recommends ‘a coordinated approach to planning and implementing should be developed to meet the identified needs of an individual with ASD, including linkage or integration and coordination of multiple services’ (NZ ASD Guideline 2008, p 21). This is one of the areas being addressed through the implementation of the New Zealand Autism Spectrum Disorder Guideline, and may result in system changes at a number of levels.

#### Practice implications

43. Ensure that all services that the NASC organisation provides, and all resources developed, show evidence of respect for the values, knowledge, preferences and cultural perspectives of the person with ASD and their family, carers, whānau and aiga.
44. Provide information to families, carers, whānau and aiga on counselling and advocacy services (although NASC organisations cannot fund these services).
45. Refer parents and informal carers to specialist ASD parent education programmes.

- 46. Support people with ASD and the people who provide them with informal support to address health needs through making linkages with health practitioners, suggesting and requesting comprehensive medical assessments, and encouraging and supporting people with ASD to have regular contact with health practitioners.
- 47. Involve families, carers, whānau and aiga in planning and implementing support services.
- 48. Plan and implement support services for people with ASD in a co-ordinated way, and address linkages and integration of multiple services. With consent from the person with ASD, or (for a child) their family, this measure includes sharing information appropriately with other services.
- 49. Include changes to or developments in the planning, co-ordination and implementation of services when updating the NASC ASD Guideline.

## 14.2 Education for learners with ASD

*Note: This section is based on NZ ASD Guideline (2008, pp 85–132)*

Through schools, Resource Teachers: Learning and Behaviour (RTLB) and Special Education, the Ministry of Education provides a range of support to learners with ASD, from their early childhood until they leave school. (For more details on its work in this area, go to [www.minedu.govt.nz](http://www.minedu.govt.nz) and search with the key word 'autism'.) Implementation of intervention across settings is important (eg, home, early childhood education, school and community). Transitions within the education system are recognised as a significant source of stress for children with ASD and require planning and preparation.

### Practice implications

- 50. With consent, inform disability service providers whenever a child with ASD is receiving support from early childhood education, schools, Resource Teachers: Learning and Behaviour, and Special Education, so that they can find out what the support is and implement the support out of school (if appropriate).
- 51. Work closely with early childhood education, schools, Resource Teachers: Learning and Behaviour, and Special Education at times of significant transition (eg, leaving school, moving from home into more independent living arrangements).

### 14.3 Treatment and management of ASD

*Note: This section is based on NZ ASD Guideline (2008, pp 133–161)*

Treatment and management of ASD should focus on the development of skills for independent living to promote independence and quality of life and minimise stress on the person with ASD and their family, carers, whānau and aiga.

People with ASD are at risk of developing behavioural and emotional difficulties from childhood, and once problems have become established they may be very difficult to change. Avoiding or minimising problems early in life is essential. Behavioural and emotional problems sometimes present as requests for changes to the person's physical environment. Comprehensive assessment and treatment planning by ASD-experienced health, education, disability and behaviour specialists are required in order to advise people with ASD and their families, carers, whānau and aiga on appropriate interventions.

Numerous approaches to ASD intervention and treatment exist and many are described in the New Zealand Autism Spectrum Disorder Guideline (NZ ASD Guideline 2008, Part 4 and Appendix 8). Not all interventions are evidence-based or supported by the NZ ASD Guideline. The mainstays of ASD interventions are supportive, educational and behavioural approaches.

'Applied behaviour analysis' describes a range of psychological techniques often used with people with ASD. The Ministry of Education has commissioned reviews on applied behaviour analysis that will be considered as part of the Living Guideline process and may result in updates to the New Zealand Autism Spectrum Disorder Guideline.

A number of medications may be helpful in significantly improving various target symptoms of ASD, and associated conditions. However no medication has been identified as a cure for ASD, and medication is only one of a range of management options. The NZ ASD Guideline recommends that health and educational professionals develop comprehensive treatment plans, and include 'behavioural needs, educational interventions, psychosocial treatments, communication, environmental and systems issues and the suitability (or not) of medication' (NZ ASD Guideline 2008, pp 133–161).

Differentiating between behavioural and mental health concerns of people with ASD can be tricky. Meeting service needs associated with co-occurring mental health conditions and addictions are the responsibility of District Health Boards. However District Health Boards do not always have a sufficient number of staff with expertise in ASD. The Ministry of Health is funding a range of initiatives to address District Health Boards' capability to better meet the needs of people with ASD.

Practice implications	
<p>52. Make timely referrals, with consent, for assessment by health, education, disability and behaviour specialists in order to avoid or minimise the development of behaviour problems.</p>	<p>57. Work closely with all relevant and involved services at times of transition.</p>
<p>53. Support people with ASD and their families, carers, whānau and aiga to engage (or re-engage) with health, education, disability and behaviour specialists in order to identify and receive advice on appropriate interventions.</p>	<p>58. Support people with ASD and their families to contact ASD DIAS and request information on the evidence supporting interventions relating to ASD.</p>
<p>54. Support people with ASD and their families, carers, whānau and aiga to consider interventions that have been recommended by health, education, disability and behavioural specialists after intervention assessment, and that:</p> <ul style="list-style-type: none"> <li>• minimise problem behaviours and issues</li> <li>• maximise safety and appropriate levels of security</li> <li>• focus on the development of skills for independent living</li> <li>• are recommended in the New Zealand Autism Spectrum Disorder Guideline.</li> </ul>	<p>59. NASC staff are aware of the Living Guideline process that provides new evidence as it is reviewed. Addendums to the NZ ASD Guideline (2008) will be published on the Ministry of Health website following review.</p>
<p>55. Develop or adjust packages of support to take into account intervention strategies recommended after comprehensive assessment by health, education, disability and behaviour specialists.</p>	<p>60. Work collaboratively with mental health services, addictions and other District Health Board services involved with a person with ASD to facilitate an integrated approach to meeting the person’s clinical and support needs.</p>
<p>56. If the recommended or required package of support exceeds current guidelines, consider alternative funding sources, make appropriate referrals and/or seek funding approval and authorisation.</p>	

#### 14.4 Living in the community

*Note: This section is based on NZ ASD Guideline (2008, pp 163–183)*

Young people and adults with ASD should be supported to transition into further education, work or other meaningful daytime activities; achieve the best possible level of residential independence; and live in the least restrictive environment possible. Periods of transition are particularly stressful for people with ASD, and require careful planning and implementation.

Further education, employment and vocational options for people with ASD require careful selection and support. Providers supporting these

transitions should have skills in working with people with ASD.

People with ASD frequently have difficulty accessing recreational opportunities. Children, young people and adults with ASD should have access to leisure facilities and meaningful activities tailored to their needs and interests. They may require support to achieve such access. Respite services for people with ASD need to be structured and predictable, and to support communication, personal independence and safe leisure skills.

People with ASD appear to be at high risk of being victims of crime, and may require support to learn safety skills, and access appropriate support if victimised. They sometimes get into legal difficulty. People with ASD need information and support when involved with the criminal justice system.

**Practice implications**

61. Work collaboratively with people with ASD and their families, carers, whānau and aiga to plan and support transitions for young people moving from school to work or vocational or further education.

62. Refer school leavers on to relevant agencies well in advance so that appropriate transition support can be arranged.

63. Work collaboratively with people with ASD and their families, carers, whānau and aiga to plan and support transitions for young people and adults moving from home into more independent living arrangements.

64. Having obtained informed consent, provide all relevant NASC information to work or vocational and educational service providers to support successful transitions.

65. Assist people to identify and access fulfilling recreational pursuits.

66. When respite services are needed, refer to services that are more structured and predictable, and that best support communication, personal independence and safe leisure skills.

67. Encourage people with ASD and their families, carers, whānau and aiga to recognise that people with ASD need to know how to keep themselves safe from abuse and what to do if they are abused, and help them access appropriate information and support.

68. Assist people with ASD who have been victimised or abused to access services from Child, Youth and Family (CYF), Victim Support, Accident Compensation Corporation (ACC) (Sensitive Claims Unit) and similar organisations.

69. Identify and provide information on appropriate support for people with ASD who become involved with the criminal justice system.

**14.5 Māori and Pacific perspectives**

*Note: This section is based on NZ ASD Guideline (2008, pp 197–220)*

There is no information on the prevalence of ASD in Māori and

Pacific peoples. Issues of importance to Māori and Pacific peoples include access to diagnosis, education and information on ASD; post diagnosis support; barriers to services; and support for families. More research is also needed in this area.

Māori and Pacific peoples need services to be culturally appropriate and sensitive to their needs. In particular, Māori are seeking kaiārahi (guides) who would work in conjunction with, and be supported across, the health, education and disability sectors involved with ASD.

**Practice implications**

70. Ensure that NASC practices are culturally safe.

71. In updating and reviewing the NASC ASD Guideline, include developments for Māori and Pacific peoples.

**15. People exiting NASC services**

NASC organisations are responsible for facilitating access to support and services for eligible disabled people, and doing so in a publicly accountable manner.

Existing Ministry-funded clients who are subsequently found to be ineligible for Ministry-funded disability support services or who will no longer benefit from these services should not have their services terminated until a transfer/exit process has been established with the person and the appropriate service area (Ministry of Health 2005b).

Transition to exit services must be considered where a person:

- is no longer eligible for Disability Support Services
- will no longer benefit from Disability Support Services, or
- does not wish to access supports. ASD DIAS can provide information on local and national ASD services.

**Practice implications**

72. Follow Ministry of Health advice on processes for transition.

73. Plan with any people with ASD currently receiving Ministry-funded disability support services (and those supporting them), who are either no longer eligible for or will no longer benefit from these services, and transition to exit services or transfer to appropriate services.

74. Consult the Ministry of Health in all cases where discussion with and prior agreement of the Ministry has been a prerequisite to providing services to a person or where there are particular risks in changing an individual's existing service package.

75. Consult the Ministry of Health (with a proposed plan) when transition out of Ministry-funded disability support services for a person with ASD triggers stress that cannot be easily managed.

76. When no alternative, responsible services exist, provide information on and contact details for ASD DIAS.

## Glossary of Terms and Abbreviations

<b>Aiga</b>	A general term for ‘family’, used across Pacific peoples.
<b>Autism</b>	A disorder characterised by more profound impairments in communication, social and restricted interests, activities and behaviours. May include intellectual impairment.
<b>Autism spectrum disorder (ASD)</b>	Encompasses a number of disorders that are characterised by problems with impairments in understanding and using verbal and non-verbal communication, in social behaviour and in the ability to think and behave flexibly, which may be shown in restricted, obsessional and repetitive activities.
<b>Asperger syndrome</b>	A disorder in the autism spectrum defined by impairments in communication and social development and by repetitive interests and behaviour. Unlike typical autism, individuals with Asperger syndrome do not have significant delay in structural aspects of language and cognitive development.
<b>Core deficit</b>	A deficit (here, in autism spectrum disorders) that is defined in diagnostic criteria.
<b>DIAS</b>	Disability Information and Advisory Service
<b>Differential diagnosis</b>	Alternative possible diagnosis. Also commonly used to mean the different diagnostic possibilities that need to be considered in a particular situation.
<b>DSS</b>	Disability Support Services, Ministry of Health
<b>GP</b>	General practitioner
<b>Intellectual disability</b>	A condition manifested before the age of 18 years, in which people have both significantly subaverage intellectual functioning and significant deficits in adaptive functioning.
<b>NASC</b>	Needs Assessment and Service Co-ordination
<b>NASC ASD Guideline</b>	This document; full title <i>Working with People with Autism Spectrum Disorder: A Guideline for Ministry of Health Needs Assessment and Service Co-ordination Organisations</i>
<b>NZ ASD</b>	New Zealand Autism Spectrum Disorder Guideline (NZ ASD Guideline 2008)
<b>Pervasive developmental disorder</b>	Another term for autism spectrum disorder.
<b>RIDCA</b>	Regional Intellectual Disability Care Agency
<b>Whānau</b>	Extended family

Note: Where possible, definitions have been taken from: NZ ASD Guideline (2008, pp 242–263).

## APPENDIX 1: Practice Implications

General area	ASD-specific area
<p><b>Training and knowledge</b> Ensure that NASC practices are culturally safe. (Practice implication 70)</p>	<p><b>Training and knowledge</b></p> <ul style="list-style-type: none"> <li>a. All staff will be aware of the NZ ASD Guideline, and designated staff will be familiar with and competent in handling ASD-related cases. (Practice implication 1)</li> <li>b. Understand the term 'autism spectrum disorder' and recognise the wide range of presentations. (Practice implication 4)</li> <li>c. Recognise the core deficits associated with ASD. (Practice implication 5)</li> <li>d. Recognise signs of ASD in young children and older people. (Practice implication 6)</li> <li>e. Be familiar with the processes outlined in the forthcoming Handbook for Recognition and Referral of Possible ASD. (Practice implication 12)</li> </ul>
<p><b>Systems and resources</b> Ensure that NASC practices are culturally safe. (Practice implication 70)</p>	<p><b>Systems and resources</b></p> <ul style="list-style-type: none"> <li>a. Record 'ASD' in the National NASC Information System, whenever a provisional or firm diagnosis of ASD, autism or Asperger syndrome is made for a person. (Practice implication 7)</li> <li>b. Ensure that people with ASD and their families, carers, whānau and aiga, all relevant agencies working with people with ASD (eg., Disability Information and Advisory Service, referrers, diagnostic clinicians, and other health and education services) are aware of the NASC organisation's role and processes. (Practice implication 13)</li> <li>c. Liaise with ASD DIAS on a regular basis for information on national and local ASD service providers, and developments in ASD. (Practice implication 24)</li> <li>d. Tailor assessment facilitation and service/care co-ordination processes to suit the personal characteristics and needs of people with ASD. (Practice implication 40)</li> <li>e. Form good working relationships with other organisations to enhance the services provided to people with ASD, minimise replication and inconsistency of approaches, and prevent inter-agency disputes. (Practice implication 42)</li> <li>f. Ensure that all services that the NASC organisation provides, and all resources developed, show evidence of respect for the values, knowledge, preferences and cultural perspectives of the person with ASD and their family, carers, whānau and aiga. (Practice implication 43)</li> </ul>

General area	ASD-specific area
<p><b>Eligibility</b> Apply eligibility criteria consistently and transparently within each NASC organisation. (Practice implication 27) Ensure that people given eligibility for a limited period are fully aware that the services they receive will be reviewed and that service provision may be temporary or time-limited and will depend on the outcome of future assessments. (Practice implication 28)</p>	<p><b>Eligibility</b></p> <ol style="list-style-type: none"> <li>a. Ensure that people with ASD fulfil the eligibility criteria of Disability Support Services (by screening, seeking additional information, and referring to current Ministry of Health policy) before offering or arranging NASC services. (Practice implication 26)</li> <li>b. Regularly review and re-assess people with ASD who have eligibility for a limited period. (Practice implication 29)</li> <li>c. Provide information on ASD DIAS to people with ASD who are not eligible for NASC services, and refer them to alternative appropriate services (if possible). (Practice implication 30)</li> <li>d. Follow specific Ministry of Health directions as they relate to specific situations. (Practice implication 31)</li> <li>e. Follow Ministry of Health advice on processes for transition. (Practice implication 72)</li> <li>f. Plan with any people with ASD currently receiving services that are no longer eligible, and process to exit services or transfer to appropriate services. (Practice implication 73)</li> <li>g. Consult with the Ministry of Health in all cases where services have been provided to an ineligible person at the explicit direction of the Ministry. (Practice implication 74)</li> <li>h. Consult with the Ministry of Health (with a proposed plan) when transition for an ineligible person with ASD triggers stress that cannot be easily managed. (Practice implication 75)</li> <li>i. When no alternative responsible services exist, NASC should provide information on and contact details for ASD DIAS. (Practice implication 76)</li> </ol>

General area	ASD-specific area
<p><b>Assessment facilitation</b></p> <p>Consider initiating referral for general developmental assessment when signs of developmental delay in early childhood are recognised. (Practice implication 8)</p> <p>Obtain informed consent before initiating referral for general developmental assessment and/or diagnostic assessment. (Practice implication 9)</p>	<p><b>Assessment facilitation</b></p> <ul style="list-style-type: none"> <li>a. Consider initiating referral for diagnostic assessment when ASD seems likely (but has not been diagnosed). (Practice implication 10)</li> <li>b. Request that behavioural or mental health assessments of a person with intellectual disability also consider diagnosis, and the possibility of ASD. (Practice implication 11)</li> <li>c. Recognise that people with ASD may have additional diagnoses or conditions that may require support. (Practice implication 14)</li> <li>d. Identify disability support needs associated with all conditions that a person has been diagnosed with. (Practice implication 15)</li> <li>e. Identify where shared support funding and/or service arrangements may be indicated and liaise with or refer to the appropriate services. (Practice implication 16)</li> <li>f. Be alert to the possibility of undiagnosed ASD in people with an intellectual disability, and refer to appropriate service. (Practice implication 17)</li> <li>g. Consider initiating referral for diagnostic assessment if it seems likely that a person has more than one diagnosis or condition. (Practice implication 18)</li> <li>h. Be knowledgeable about ASD before making initial contact. (Practice implication 32)</li> <li>i. Before meeting become aware of the strategies needed to ensure the physical, emotional and cultural safety of all involved, and use these strategies on meeting. (Practice implication 33)</li> <li>j. Be sensitive to the discomfort that people may experience during assessment facilitation. (Practice implication 34)</li> <li>k. Identify natural networks and community resources. (Practice implication 35)</li> <li>l. Reassure people that identification of strengths, resources and successful strategies will not hinder support and is not conducted with the sole intention of removing support. (Practice implication 36)</li> <li>m. Provide accurate and timely information when support needs cannot be met by existing contracts and services. (Practice implication 37)</li> <li>n. Wherever possible, arrange for assessment facilitation and service co-ordination to be carried out by the same NASC staff member, if that is the preference of the person with ASD or their and their family, carers, whānau and aiga. (Practice implication 38)</li> <li>o. Identify the strengths and resources of a person with ASD and their family, carers, whānau and aiga. (Practice implication 39)</li> <li>p. Recognise the barriers to successful assessment facilitation that can arise from the symptoms of ASD, work to overcome these barriers. (Practice implication 41)</li> </ul>

General area	ASD-specific area
<p><b>Service co-ordination</b> Always obtain informed consent before sharing any information or making referral for services. (Practice implication 21) Service co-ordination</p>	<p><b>Service co-ordination</b></p> <ul style="list-style-type: none"> <li>a. Provide people with ASD, and their families, carers, whānau and aiga, with appropriate and accessible information about ASD, sources of further information on ASD, and information on NASC organisation’s role and processes. (Practice implication 19)</li> <li>b. Consider support, both within existing natural networks and funded services, that strengthens family resilience (eg, carer support and respite care) and that helps the family stay together. (Practice implication 20)</li> <li>c. Establish if early intervention is occurring (or if referral has been initiated) for any child referred to a NASC organisation who has a provisional or confirmed diagnosis of ASD (Practice implication 22)</li> <li>d. Initiate early intervention services through referral to Special Education, the GP and health specialists. (Practice implication 23)</li> <li>e. Provide people with ASD with contact details for ASD DIAS. (Practice implication 25)</li> <li>f. Wherever possible arrange for assessment facilitation and service co-ordination to be carried out by the same NASC staff member, if that is the preference of the person with ASD and their family, carers, whānau and aiga. (Practice implication 38)</li> <li>g. Provide information to families, carers, whānau and aiga on counselling and advocacy services (although NASC organisations cannot fund these services). (Practice implication 44)</li> <li>h. Refer parents and informal carers to specialist ASD parent education programmes. (Practice implication 45)</li> <li>i. Support people with ASD and the people who provide them with informal support to address health needs through making linkages with health practitioners, suggesting and requesting comprehensive medical assessments, and encouraging and supporting people with ASD to have regular contact with health practitioners. (Practice implication 46)</li> <li>j. Involve families carers, whānau and aiga in planning and implementing support services. (Practice implication 47)</li> <li>k. Plan and implement support services for people with ASD in a co-ordinated way, and address linkages and integration of multiple services. With consent from the person with ASD or (for a child) their family, this measure includes sharing information appropriately with other services. (Practice implication 48)</li> <li>l. Reassure people that identification of strengths, resources and successful strategies will not hinder support and is not conducted with the sole intention of removing support. (Practice implication 33)</li> <li>m. Work closely with early childhood education, schools, Resource Teachers: Learning and Behaviour, and Special Education at times of significant transition (eg, leaving school, moving from home into more independent living arrangements). (Practice implication 51)</li> </ul>

General area	ASD-specific area
<p><b>Service co-ordination continued</b></p>	<p><b>Service co-ordination continued</b></p> <p>n. Make timely referrals for assessment by health, education, disability and behavioural specialists in order to avoid or minimise the development of behaviour problems. (Practice implication 52)</p> <p>o. Support people with ASD and their families, carers, whānau and aiga to engage (or re-engage) with health, education, disability and behaviour specialists in order to identify and receive advice on appropriate interventions. (Practice implication 53)</p> <p>p. Support people with ASD and their families, carers, whānau and aiga to consider interventions that have been recommended by health, education, disability and behavioural specialists after intervention assessment, and that:</p> <ul style="list-style-type: none"> <li>• minimise problem behaviours and issues</li> <li>• maximise safety and appropriate levels of security</li> <li>• focus on the development of skills for independent living</li> <li>• are recommended in the New Zealand Autism Spectrum Disorder Guideline. (Practice implication 54)</li> </ul> <p>q. Develop or adjust packages of support to take into account intervention strategies recommended after comprehensive assessment by health, education, disability and behaviour specialists. (Practice implication 55)</p> <p>r. If the recommended or required package of support exceeds current guidelines, consider alternative funding sources, make appropriate referrals, and/or seek funding approval and authorisation. (Practice implication 56)</p> <p>s. Work closely with all relevant and involved services at times of transition. (Practice implication 57)</p> <p>t. Support people with ASD and their families to contact ASD DIAS and request information on the evidence supporting interventions relating to ASD. (Practice implication 58)</p> <p>u. Work collaboratively with mental health services, addictions and other District Health Board services involved with a person with ASD to facilitate an integrated approach to meeting the person’s clinical and support needs. (Practice implication 60)</p> <p>v. Work collaboratively with people with ASD and their families, carers, whānau and aiga to plan and support transitions for young people moving from school to work or vocational or further education. (Practice implication 61)</p> <p>w. Refer school leavers on to relevant agencies well in advance so that appropriate transition support can be arranged. (Practice implication 62)</p> <p>x. Work collaboratively with people with ASD and their families, carers, whānau and aiga to plan and support transitions for young people and adults moving from home into more independent living arrangements. (Practice implication 63)</p> <p>y. Having obtained informed consent, provide all relevant NASC information to work or vocational and educational service providers to support successful transitions. (Practice implication 64)</p>

General area	ASD-specific area
<p><b>Service co-ordination continued</b></p>	<p><b>Service co-ordination continued</b></p> <ul style="list-style-type: none"> <li>z. Assist people to identify and access fulfilling recreational pursuits. (Practice implication 65)</li> <li>aa. When respite services are needed, refer to services that are more structured and predictable, and that best support communication, personal independence and safe leisure skills. (Practice implication 66)</li> <li>bb. Encourage people with ASD and their families, carers, whānau and aiga to recognise that people with ASD need to know how to keep themselves safe from abuse and what to do if they are abused, and help them access appropriate information and support. (Practice implication 67)</li> <li>cc. Assist people with ASD who have been victimised or abused to access services from Child, Youth and Family (CYF), Victim Support, Accident Compensation Corporation (ACC) (Sensitive Claims Unit) and similar organisations. (Practice implication 68)</li> <li>dd. Identify and provide information on appropriate support for people with ASD who become involved with the criminal justice system. (Practice implication 69)</li> </ul>
<p><b>Currency of NASC procedures</b></p>	<p><b>Currency of NASC ASD Guideline</b></p> <ul style="list-style-type: none"> <li>a. Review Working with People with Autism Spectrum Disorder: A Guideline for Ministry of Health Needs Assessment and Service Co-ordination Organisations (the NASC ASD Guideline) and update it according to changes in systems, services, policies, and the information on and evidence base of ASD. (Practice implication 2)</li> <li>b. NASC organisations hold together in one reference package: the New Zealand Autism Spectrum Disorder Guideline; Working with People with Autism Spectrum Disorder: A Guideline for Ministry of Health Needs Assessment and Service Co-ordination Organisations; current Ministry of Health policy documents; and all relevant ASD documents developed as part of the process of implementing the New Zealand Autism Spectrum Disorder Guideline. (Practice implication 3)</li> <li>c. Include changes to or developments in the planning, co-ordination and implementation of services when updating the NASC ASD Guideline. (Practice implication 49)</li> <li>d. Refer to or incorporate information from reviews of applied behaviour analysis in later versions of the NASC ASD Guideline. (Practice implication 59)</li> <li>e. In updating and reviewing the NASC ASD Guideline, include developments for Māori and Pacific peoples. (Practice implication 71)</li> </ul>

## APPENDIX 2: References and Bibliography

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## APPENDIX 3: People Consulted

Consumers	NASC Managers & Staff	Ministry Officials
<ul style="list-style-type: none"> <li>• Kris Appleby, Consumer (Parent) and Advocate</li> <li>• Wendy Duff, Parent, National Operations Manager of Autism New Zealand, and Member of the New Zealand Autism Spectrum Disorder Guideline Implementation Advisory Group</li> <li>• Matt Frost, Consumer and Chair of the New Zealand Autism Spectrum Disorder Guideline Implementation Advisory Group, Policy and Information Researcher, CCS Disability Action National Office</li> <li>• John Grealley, Parent and Consumer</li> </ul>	<ul style="list-style-type: none"> <li>• Rhonda Anderson, Access Ability Otago Southland</li> <li>• Laurence Bartup, Capital Support</li> <li>• Sandra Cistrone, Taikura Trust</li> <li>• David Darling, Capital Support</li> <li>• Renee Delamere, Support Net</li> <li>• Rosalie Eilering, Northable</li> <li>• Jacinta Hall, Supportlinks</li> <li>• Marlon Hepi, LIFE Unlimited</li> <li>• Craig Hutchison, Lifelinks</li> <li>• Adri Isbister, LIFE Unlimited</li> <li>• Helen O'Connell, LIFE Unlimited</li> <li>• Jane Pembroke, LIFE Unlimited</li> <li>• Nicky Rendell, Life Links</li> <li>• Sue Robertson, Access Ability</li> <li>• Anne Simpson, Lifelinks</li> <li>• Pamela Tailby, Focus</li> <li>• Tania Teinakore, Taikura Trust</li> <li>• Kaye Thomas, Northable</li> <li>• Margaret Thomson, Disability Support Link</li> <li>• Jan White, Disability Support Link</li> </ul>	<ul style="list-style-type: none"> <li>• Joanna Curzon, Team Leader: Research, Professional Practice, Ministry of Education</li> <li>• Jenny Moor, Development Manager, Service Access Team, Disability Support Services, Health and Disability National Services Directorate, Ministry of Health</li> <li>• Karen Hunter, Development Manager, Family and Community Support Team, Disability Support Services, Health and Disability National Services Directorate, Ministry of Health</li> <li>• Marsha Marshall, Manager, Family and Community Support Team, Disability Support Services, Health and Disability National Services Directorate, Ministry of Health</li> </ul>

## **APPENDIX 4: ASD Disability Information and Advisory Service Providers** *(September 2009)*

Altogether Autism  
0800 ASD INFO (0800 273 463)  
[info@altogetherautism.org.nz](mailto:info@altogetherautism.org.nz)  
[www.altogetherautism.org.nz](http://www.altogetherautism.org.nz)

Autism New Zealand  
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