

New Zealand Autism Spectrum Disorder Guideline Summary





Cover artwork by Daniel Phillips.

Daniel is a person with autism who works at the Petone Arthouse, a vocational service of IDEA Services. He has been working at the Arthouse for over a decade and is a prolific painter. His greatest ambition is to go on the Eurostar train from London to Paris through the Channel Tunnel and is currently raising money through his art for this goal.

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New Zealand
Autism Spectrum Disorder
Guideline Summary

Whakapūpūtia mai ō mānuka kia kore ai e whati
Cluster the branches of the mānuka so that they will not break

Voices

People with ASD and their families/whānau

“After diagnosis, there is often a ‘black hole’ for families”¹.

“Stephen is completely content and forever happy with his life. He seems to remind me [his father] that I have been driven and controlled by individualism, materialism and sensationalism. He seems to tell me that I worry too much about my individual accomplishments, what I should say and how people would respond or react to what I say ... and so forth”².

“I feel that therapy is good only if its goal is to help the autistic person to fully develop into a whole happy person. Therapy that focuses on the forcing of repeated actions ... is degrading”³.

“In the first grade, the class was directed to print the letters of the alphabet. As I printed them, I drew complete letters on the paper, copying as I had seen them in newspapers and books. The teacher and everyone else in the class only drew line figures of letters, and I thought I was in a room full of nonconformists, who drew incomplete letters as though they were right and the whole world was wrong”⁴.

“It is not wrong to think in a different way”⁶.

“It’s like attacking a seven-headed monster; you don’t know which head to attack first”¹.

“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”⁵.

“I do want to stress that people with autism should be helped to the point where they can help themselves. We need the best treatment and education we can get”⁶.

“I feel close to my mum, stepfather, and sister, and sometimes I do things with them.... Most of the time, I prefer to be alone to pursue my interests”⁵.

“I don’t want to be like anybody else. I don’t necessarily see the idea of NT [neurotypical] as perfection. Hey regular people do stupid mean and often evil things that people with autism would never do”⁷.

“I am proud of who I am and autism is part of who I am. In fact, you can’t separate the autism from what I do, think or am”⁶.

"I am tired of having to do 100% of the changing, and there is no change with most people without autism"⁷.

"My mum came to school at the beginning of each year and talked to both the students and the teachers about autism and about me. I think that helped everyone understand me better. I especially liked it when she talked about all the things I am good at"⁵.

"Education should be equal for all. And appropriate for all, but it must be chosen individually. If adaptations and supports are needed so that children with autism can learn, make them. If methods or materials need to be provided so that children with autism can succeed, provide them. Segregation of any kind is wrong"⁶.

"People who know the details about my autism are usually more comfortable dealing with me. Also, the more information my teachers have, the more ideas they have to help me learn"⁵.

"I am sick of social skills groups... Why can't someone go to the bar with me or to chess club?"¹⁰

"Parents become highly educated – of necessity, not of choice"⁸.

"I have not 'recovered' from autism. I believe that no human being should be ashamed of who he or she is"³.

"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"⁷.

"I couldn't cope any more so I left him sleeping, went to the shopping centre because I really, really needed a break. But the neighbours must have been watching and when I came back, the police were there and then CYF were involved. After that, I got help but I had to reach a crisis first. Why couldn't I get help first?"⁹

"Even if I was capable of having a relationship, it's just too hard to meet somebody. You know it's like I might have a heart of gold but there's no way for people to know that. All they see is the autism"¹⁰.

Contents

Overview	5
Disclaimer	5
Caveat	5
Purpose of the New Zealand Autism Spectrum Disorder Guideline	6
About the New Zealand Autism Spectrum Disorder Guideline	7
Autism Spectrum Disorder Guideline Development Process	7
Executive Summary	10
References	23

Overview

Disclaimer

Evidence-based practice guidelines are produced to assist health professionals, educators and consumers make decisions about education and optimum care in specific clinical circumstances. Research has shown that if properly developed, communicated and implemented, guidelines can improve care. The advice in this guideline is based on epidemiological studies and other research evidence. Where no evidence is available, but guidance is needed, recommendations for best practice have been developed through a systematic consensus process.

The recommendations in this guideline do not indicate an exclusive course of treatment or serve as an absolute standard of care or education. While guidelines represent a statement of best practice based on the latest available evidence (at the time of development), they are not intended to replace the professional's judgment in each individual case.

Caveat

As a result of feedback received during consultation, an additional independent review of applied behaviour analysis (ABA) is currently being undertaken. The purpose of the review is to critically appraise published research about ABA interventions in relation to outcomes for people with autism spectrum disorder (ASD).

The current sections of the New Zealand ASD Guideline which relate to ABA will be neither reviewed nor amended until the independent review is completed. The recommendations and evidence from the review will be considered by the ASD Living Guideline Working Group using publicly available criteria that will be applied to all proposed changes to the Living Guideline (see page 9 for an explanation of the Living Guideline).

Purpose of the New Zealand Autism Spectrum Disorder Guideline

This guideline intends to provide guidance on autism spectrum disorder (ASD) in both children and adults in New Zealand. The guideline is an evidence-based summary that covers identification and diagnosis of ASD, and ongoing assessment and access to interventions and services for individuals with ASD. It seeks to provide the best evidence currently available to aid informed decision-making to improve the health, educational and social outcomes for people with ASD. The guideline is for use by primary care practitioners, education professionals, policy makers, funders, parents, carers, specialists and any others who provide for people with ASD.

The Summary of the New Zealand Autism Spectrum Disorder Guideline (ASD Guideline) presents the key recommendations from each section of the guideline. The summary also provides a brief outline of the processes followed to develop the guideline.

About the New Zealand Autism Spectrum Disorder Guideline

Autism Spectrum Disorder Guideline Development Process

Background

For the first time in New Zealand, an ASD Guideline will provide evidence-based information for health, disability and education professionals and social service agencies who provide services for people with ASD, their families and whānau.

In 1998, the Government commissioned a review of autism services, now known as the Curry Report, across key sectors. The review identified gaps in services and made some recommendations to improve the quality of autism spectrum disorder (ASD) related services. Key issues included a lack of coordinated services and cross-government leadership difficulties.

In September 2002, in response to the recommendations in the Curry Report, the Ministry of Health and the Ministry of Education, in conjunction with the Paediatric Society of New Zealand started work on scoping an ASD Guideline. In December 2002, an ASD Guideline Steering Group was set up to help guide the work of the guideline project team. The group helped to ensure that service users' perspectives were included in the guideline, promoted awareness of cultural and migrant issues and helped build the credibility of the project within the community. The Steering Group included representation from: adults with ASD, parents/families of people with ASD, the Paediatric Society of New Zealand, the Faculty of Child and Adolescent Psychiatry of the Royal Australia and New Zealand College of Psychiatrists, disability provider organisations, Needs Assessment Service Coordination (NASC) services, Child, Youth and Family (CYF), Pacific

advisers, school principals, early intervention services, the Ministry of Education, Special Education (GSE), and the Disability Services, Māori Health, Clinical Services, and Mental Health Directorates within the Ministry of Health. The members of the Steering Group are listed in Appendix 2 of the ASD Guideline.

An ASD Cross Government Officials Group oversaw the development of the guideline and provided regular updates for their respective Ministers.

Structure of the ASD Guideline

The guideline is divided into eight parts. Part 1 covers the identification and initial assessment of children, young people and adults with ASD. Part 2 focuses on how best to provide support to people who share their lives with individuals who have ASD. It also outlines the personal health needs of people with ASD. Part 3 covers educational principles and interventions for children and young people growing up with ASD and guidance for education-sector organisation and management. Part 4 covers the management of behavioural, emotional and mental health difficulties that can be experienced by people with ASD and provides evidence-based guidance on how these difficulties can be prevented, minimised or eased. Part 5 focuses on the support needs of people with ASD within the community setting, covering various aspects from transitioning from secondary school into adulthood to dealing with the criminal justice system. Part 6 focuses on the professional learning and development needs for individuals or groups who come into contact with people with ASD, from awareness raising to highly specialised training. Parts 7 and 8 cover the perspectives and experiences of Māori and Pacific people with ASD and explore issues of information needs, diagnosis, assessment, support, access, services and treatment decisions for these populations.

Process of development

The ASD Guideline was written by three workstreams with experienced Māori and Pacific researchers. The three workstreams, each with a particular expertise, were set up to represent different aspects of ASD and the different contexts in which people with ASD live, learn, work and play.

The Paediatric Society of New Zealand led Workstream 1 under contract to the Ministry of Health. It addressed assessment, diagnosis and pharmacotherapy in children. The Ministry of Education led Workstream 2 which addressed management in the education sector and professional learning and development issues for professionals and parents. The Ministry of Health funded Workstream 3 which focused on issues in older children and adults, including diagnosis, assessment and interventions, as well as support across the age spectrum. Stakeholder reference groups were set up to provide input to these workstreams from a wide range of providers and agencies. The results from this process were merged to provide an integrated approach to management issues. A Māori Advisory group set up by the Ministries of Health and Education, plus

a series of nationwide hui provided Māori input. Pacific input was provided by a fono and the subsequent work of a Pacific researcher. The Guideline has separate Māori and Pacific chapters on the management of ASD in a culturally appropriate manner.

Different contributors to the ASD Guideline followed separate methodologies. Workstream 1 adapted the United Kingdom National Autism Plan for Children 2003¹¹ to New Zealand circumstances for the assessment and diagnosis of children in Part 1 of the guideline. Broad evidence-based principles (development of practice questions, identification and appraisal of evidence to answer the questions, development of evidence tables and graded recommendations based on the body of evidence) guided the development of all other parts.

You can find the lists of practice questions and the evidence tables that provided the basis for the recommendations at www.moh.govt.nz/autismspectrumdisorder

Recommendations have been graded according to the system used by the New Zealand Guidelines Group (www.nzgg.org.nz).

Recommendations:	Grade
The recommendation is supported by GOOD evidence (where there are a number of studies that are valid, applicable and clinically relevant).	A
The recommendation is supported by FAIR evidence (based on studies that are mostly valid, but there are some concerns about the volume, consistency, applicability and/or clinical relevance of the evidence that may cause some uncertainty, but are not likely to be overturned by other evidence).	B
The recommendation is supported by EXPERT OPINION only (from external opinion, published or unpublished, eg, consensus guidelines).	C
No recommendation can be made. The evidence is insufficient (either lacking, of poor quality or conflicting and the balance of benefits and harms cannot be determined).	I

Where a recommendation is based on the clinical and educational experiences of members of the guideline development teams, it is referred to as a good practice point.

Good Practice Point:	
Where no evidence is available, best practice recommendations are made based on the experience of the guideline development teams or feedback from consultation within New Zealand.	✓

Further details of the process are provided in Appendix 1 of the ASD Guideline.

From December 2006 to March 2007, a four-month written consultation process and an expert peer review were undertaken. Feedback was sought from across the health, education, disability and social service sectors, and contributors were asked to declare any competing interests. There were no competing interests declared by any contributors to the ASD Guideline.

The Ministries of Health and Education, which are part of the New Zealand Crown, have jointly developed and funded the ASD Guideline and are the copyright owners of the ASD Guideline and summary documents. Please refer to the Copyright, adaptation and updating section of the ASD Guideline for full copyright information.

ASD Guideline review process

The ASD Guideline will be printed and distributed throughout New Zealand. There will be an online version of the guideline for alternative access. The guideline will be reviewed as new evidence becomes available, using a 'living guideline' approach. The 'living guideline' approach requires a small team to provide ongoing systematic monitoring of all new evidence on ASD to ensure that recommendations do not become out of date. A reprint of the guideline document will be looked at within five years of the date of publication.

Additional procedures for updating the ASD Guideline will follow the NZGG policy and practice at that time, as detailed on the website www.nzgg.org.nz

Executive Summary

Based on recent overseas data, ASD (autism spectrum disorder) is thought to affect more than 40,000 New Zealanders. It imposes significant and often serious disability on the individuals affected and creates major stresses for those who care for or educate them. Since its first description over 50 years ago, ASD has been the subject of intensive research and a great deal is now known about how to improve the effects of the disorder, although there is no known 'cure'.

The ASD Guideline addresses identification, assessment, diagnosis, interventions and services for individuals with ASD. These topics are covered in separate parts of the guideline, according to the following structure:

Part 1: Diagnosis and initial assessment of ASD

Part 2: Support for individuals, families and carers

Part 3: Education for learners with ASD

Part 4: Treatment and management of ASD

Part 5: Living in the community

Part 6: Professional learning and development

Part 7: Māori perspectives

Part 8: Pacific peoples' perspectives

For each of these major areas, the guideline development team have identified key recommendations.

The term ASD is used here to refer to the group of pervasive developmental disorders that includes classical autism and Asperger syndrome. It also includes individuals with similar features who do not fit into these diagnostic categories (*see Appendix 4 of the ASD Guideline, Diagnostic criteria for ASD*). The spectrum of autism disorders is now recognised as covering a wide range of severity and intellectual ability, from the person with the severe impairment of classical autism to a

'high functioning' individual with Asperger syndrome.

Those diagnosed with ASD all display:

- 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 appear as restricted, obsessional or repetitive activities.

These are all-encompassing features of the individual's functioning, although their intensity may vary depending on the context and the person's emotional state.

Part 1: Diagnosis and initial assessment of ASD

Part 1 of the ASD Guideline focuses on the diagnosis and initial assessment of children, young people and adults with ASD. The earlier the diagnosis of ASD is made, the greater the impact early intervention has, resulting in fewer challenging behaviours and better outcomes for families and whānau. The identification of children with ASD usually occurs through parents and their general practitioner (GP) or, at a later stage, through a child's teachers. It is important that primary care professionals monitor developmental milestones at Well Child visits to ensure early identification. All health care and education professionals need to be alert to possible signs of ASD and be open to parents' concerns about their children.

Concerns about more able children with ASD may not develop until children are exposed to the greater social demands of early childhood education or the primary school environment. The guideline provides key signs for identifying ASD in children in separate age bands: 1 to 3 years and 4 to 8 years.

Diagnosis is also important in young people in their teens and adults, although for some of these people diagnosis may only be of academic

interest. Others, however, may suffer undue stress, miss out on effective treatment options and receive inappropriate medical, psychiatric and educational interventions if diagnosis is missed. Telling a person that they have been diagnosed with ASD should be done sensitively, giving the person enough time to ask questions, to understand what is being said and to voice concerns. Families, whānau and support people may need to be involved when the diagnosis is given, especially when a young person is involved.

Assessment is the process of gathering information about the health, education and care needs of a person with ASD and his or her family. It results in the development of an action plan to meet these needs.

ASD is a developmental disorder. Its presentation will vary with age and will vary over time in any individual. In New Zealand, there is inconsistent and inequitable access to assessment and diagnosis. Young people and adults have no clearly identified pathways for assessment. Multidisciplinary assessment through specialist ASD services is recommended for all people suspected of having ASD. The multidisciplinary team approach leads to more robust diagnosis and assessment, more accurate planning of future services and supports, and reduces repetition and redundancy in the assessment and diagnostic process. Professionals providing assessment and diagnostic services for children, young people and adults with possible ASD also need to consider other possible diagnoses (such as the differential diagnosis).

Assessment tools, checklists and rating scales may aid clinical judgment. Suggestions for diagnostic tools and the role of cognitive assessment in individuals with ASD are found in Appendices 5 and 6 of the ASD Guideline. However, the applicability of diagnostic and assessment tools to a New Zealand population has not been established and research is needed to determine this.

Key Recommendations for Diagnosis and Initial Assessment	Grade
1. Early identification of children with autism spectrum disorder is essential. Early identification enables early intervention and is likely to lead to better function in later life. Early identification is achieved by: <ul style="list-style-type: none"> a. comprehensive developmental surveillance of all children so deviations from normal development are recognised early b. valuing and addressing parental concerns about their child’s development c. prompt access to diagnostic services. 	B
2. All District Health Boards (DHBs) should have in place processes that ensure: <ul style="list-style-type: none"> a. referral pathways for children and adults who may have ASD or another developmental problem are clearly understood by professionals b. services are coordinated within and across sectors c. multidisciplinary, multiagency assessments are provided d. all services are provided in a timely manner. 	C
3. All children suspected of having ASD or another developmental problem should have an audiology assessment.	✓

Key Recommendations for Diagnosis and Initial Assessment	Grade
4. Preferably, a multidisciplinary team of health care practitioners experienced in ASD should undertake diagnostic assessment of young people and adults suspected of having ASD. Without an assessment team, a health care practitioner trained and highly experienced in ASD may undertake diagnostic assessment.	B
5. Diagnostic assessment of young people and adults should be comprehensive and involve the person concerned in interview and observation.	C
6. Health care professionals must have a good understanding of the different forms of expression of ASD symptomatology across developmental stages and the symptomatology of common coexisting and alternative conditions.	B

Part 2: Support for individuals, families and carers

Part 2 deals with the needs of people who share their lives in personal and professional capacities with people with ASD. It also deals with the health support needs of people with ASD.

The needs of those who share their lives with people with ASD are extensive. ASD is sometimes regarded as a 'hidden' disability that affects every aspect of a person's day-to-day life, including social inclusion. Typically, family members and partners are key people in the lives of the person with ASD. Their additional needs for support must be considered to ensure that they, too, enjoy social inclusion to the degree that other community members take for granted. Provision of information on ASD is seen as crucial by parents and families. It should be available in various formats and take into account differing needs, both geographic and cultural. Effective educational programmes for parents and families lead to improved outcomes both for people with ASD and their carers and families.

The health care needs of a person with ASD can be complex. Appropriate management of these needs can be aggravated by the symptoms of ASD itself. Specific health care needs, such as poor dental hygiene, sleep disturbance, sensory impairment and unpredictable drug reactions, underscore the importance of a comprehensive medical assessment for people with ASD. In New Zealand, the health care of children with ASD is usually monitored by a general practitioner (GP), paediatrician and/or other child-health professionals, but specialist input usually ends when the person reaches adulthood. Some adults with ASD avoid visiting health or related services because of anxiety or fear, previous negative experiences and/or social and communication difficulties. Therefore, some people with ASD need support to manage their physical well-being appropriately, and health care professionals need knowledge of ASD and how it affects their clients to be able to provide the best health care services.

Since ASD is a diverse condition with a wide range of impairment, age at diagnosis, intellectual ability, personal needs and health status, a range of customised supports and services will be needed. An individualised approach to service delivery is particularly important and the need for service coordination is paramount. These challenges will need to be addressed.

Key Recommendations for Support for Individuals, Families and Carers	Grade
1. The values, knowledge, preferences and cultural perspectives of the family should be respected and evident in services and resources.	C
2. ASD-related counselling and/or advocacy services and education should be available to all family members and carers.	C
3. Family members need to know how to find and access information and support. Health authorities and support groups must work together to develop appropriate support services for adults and their partners to ensure sources of support and information are available.	C
4. A key service to support families is providing information about ASD. Information needs to be accessible to all people, including translated material, easy-to-read versions and developmentally appropriate information. Support groups and government should work in close association to ensure all information is kept up to date.	C
5. Individualised support should be available to people with ASD who need assistance to manage their physical well-being and health care.	C
6. Medical and health care practitioners should consider the symptomatology of their ASD clients/patients and adapt their practices and procedures accordingly.	C
7. All children should be fully immunised including the MMR vaccine (Measles, Mumps and Rubella) in accordance with the New Zealand Immunisation schedule. There is no scientific evidence to support the view that this vaccine has a role in causing ASD.	A
8. Health-promotion campaigns should ensure that people with ASD are included as a specific target group.	C
9. Sensory issues in people with ASD should be identified and appropriately assessed by occupational therapists with experience in ASD. These assessments should lead to specific recommendations.	B
10. Methodologically rigorous research is needed to examine the effectiveness of current evaluation methods and treatments used to address sensory issues.	B
11. Family support services should be flexible and timely. Families and service users should have direct involvement in planning and implementation of service provision.	C C
12. A coordinated approach to planning and implementing services should be developed to meet the identified needs of an individual with ASD, including linkage or integration and coordination of multiple services.	✓

Part 3: Education for learners with ASD

Part 3 aims to provide best-evidence guidance for professionals who work with children and adolescents with ASD in educational settings. Overall, the evidence is clear that, regardless of the intervention, implementation across home, early childhood education, school and community settings is important to the outcomes. Given the diversity of individuals with ASD, a wide range of support and intervention is needed. It is unlikely there will ever be a single approach or solution that will meet the needs of all learners with ASD, so models should be chosen to fit the characteristics of the person and the learning situation.

Most overseas educational intervention programmes are based on three broad models: discrete trial training (DTT), approaches that draw on recent behavioural and developmental research, and developmental (social pragmatic) approaches. Some comprehensive programmes have used elements of all three models and they each have something to offer in certain situations. However, no one approach has been shown to be more effective than another. Currently, special education practice in New Zealand emphasises participation and development, rather than treatment or 'fixing' the child.

There is good agreement that best practice for learners with ASD is not achieved by teaching in isolated settings away from other children, and that the quality of an intervention is at least as important as its duration. Generalisation of learning is crucial and is best achieved by working collaboratively with both teachers and parents. Other characteristics of successful learning programmes are also discussed.

Section 3.2 of the ASD Guideline looks in detail at several different curriculum areas for children and young people with ASD in the educational setting and how they influence learning.

It covers:

- communication and literacy skills
- social development
- sensori-motor development
- cognitive development and thinking skills
- self-management skills and addressing challenging behaviour.

For each of these areas, the ASD Guideline assesses the evidence for effective interventions and the implications for professional practice and the classroom. Strategies for supporting young people in secondary school are also discussed.

The decision that parents must make about where to place their child with ASD within an educational setting is important and parents need to be given balanced information about the different options. Members of staff need to have a positive attitude, expertise in ASD, and understanding and willingness to work in a team with the family. Transitions for learners with ASD need to be carefully planned to minimise stress.

Key Recommendations for Education for Learners with ASD	Grade
1. Interventions should start early, as soon as significant developmental delay is recognised, and be proactive. The child or young person's programme should be individualised and designed to engage the child or young person and provide a highly supportive environment.	B
2. Services should be available to ensure a young child is appropriately engaged across a variety of home, educational and community settings in goal-directed activities for 15 to 25 hours per week.	B
3. Formal assessments should always be supplemented by informal assessments which include observations across a variety of settings and activities and interviews with significant adults.	C
4. Generalisation and maintenance needs to be carefully planned. The learning of new skills should take place in the child or young person's usual environment, ie, with their usual carers and teachers, and with access to peers who do not have ASD.	B
5. There is no evidence that any single model is effective for teaching every goal to all children with ASD. Models should be chosen to fit the characteristics of the child and the learning situation.	B
6. Spontaneous communication, socialisation and play goals should be a priority.	A
7. The child or young person's particular interests should be incorporated whenever possible.	C
8. Children and young people should receive carefully planned and systematic instruction tailored to their individual needs and abilities.	B
9. Interventions should be monitored and evaluated on an ongoing basis. Where there is no evidence of progress within a few months, changes should be made to the curriculum or intervention goals, the time set aside for instruction, the intensity of the instruction (such as lower teacher-child ratios) or increasing consultation and support for staff.	A
10. Educational interventions should incorporate principles of positive behaviour support, particularly a focus on understanding the function of the child or young person's behaviour.	A
11. All transitions for students with ASD should be carefully planned and the child or young person and the new environment carefully prepared.	B

Part 4: Treatment and management of ASD

Part 4 covers the management of behavioural, emotional and mental health difficulties that can be experienced by children, young people and adults with ASD. Although some of these difficulties can be prevented or minimised by interventions with a totally educational approach, other interventions with a different focus may also be needed.

People with ASD are at risk of developing behavioural and emotional difficulties from childhood. Once problem behaviours have become established, they are not likely to decrease without intervention and are more likely to worsen than improve. Minimising or avoiding the development of problem behaviours early in life is essential. Long-term difficulties may arise if the communicative, social and ritualistic/obsessive aspects of ASD are not addressed.

The first step in the treatment of behavioural, emotional and mental health problems is a comprehensive assessment which takes into account the family, social and cultural context. Comprehensive treatment plans include components that address behavioural needs, educational interventions, psychosocial treatments, communication and the suitability (or not) of medication.

The mainstays of treatment are supportive, educational and behavioural approaches. No medication has been identified as a cure for ASD and the use of behavioural and environmental strategies for managing challenging behaviour should always be considered before using pharmacotherapy. However, a number of medications may be helpful in significantly improving various target symptoms and associated conditions. There is very limited information on long-term safety, particularly of some of the newer medications and there are added challenges when the person with ASD has a co-morbidity. When prescribing medications, clinicians should consult other appropriate references for comprehensive information on adverse effects and interactions.

Even after the use of well-implemented behavioural strategies or medications, a small number of people with ASD will develop serious or dangerous behaviours. Strategies for these situations are discussed. The role of clinical services is also outlined.

Key Recommendations for Treatment and Management of ASD	Grade
1. Treatment should encourage functional development, skills for independent living to minimise stress on the person with ASD and their family and whānau.	B
2. Pre-treatment assessments should gather detailed information on behavioural, emotional and mental health difficulties, address differential diagnosis, screen for medical conditions and address environmental issues.	B
3. Treatment plans should be comprehensive, and include behavioural needs, educational interventions, psychosocial treatments, communication, environmental and systems issues and the suitability (or not) of medication.	B
4. Professionals, people with ASD, family, whānau and carers should work together to evaluate treatment approaches before and during implementation.	C

Key Recommendations for Treatment and Management of ASD	Grade
5. All behavioural interventions should be of good quality and incorporate the following principles: person-centred planning, functional assessment, positive intervention strategies, multifaceted interventions, focus on environment, meaningful outcomes, focus on ecological validity and systems-level intervention.	C
6. The feasibility of setting up publicly funded, ASD-specific behavioural services should be looked into.	C
7. SSRIs (eg, fluoxetine) may be effective for some children with ASD and high anxiety and/or obsessive symptoms. However, without quality evidence, these drugs should be used with caution and careful monitoring. There is insufficient evidence to make any recommendation about the use of other types of antidepressants.	B
8. The antipsychotic medication risperidone is effective in reducing aggressive behaviour, irritability and self-injurious behaviour in children with ASD. It should be used with caution because of the high risk of adverse effects and the uncertainty about long-term effects. Monitoring for side effects should be carried out on a regular basis.	B
9. A number of other medications may be helpful in significantly improving various target symptoms and associated conditions. The choice of medication will be guided by the clinician's assessment of the symptom to be targeted by the intervention. Clinicians and interested others should refer to the full discussion of pharmacotherapy in ASD in the guideline.	C
10. When severe behaviours are evident, people with ASD need to be assessed for co-morbid conditions such as seizures, attention deficit hyperactivity disorder (ADHD), anxiety disorders and depression.	C
11. In severe or life-threatening situations, medication may be the best therapy.	C
<p>IMPORTANT NOTE FOR PRESCRIBERS:</p> <p>As prescribing information may change during the currency of this guideline, we have deliberately not provided full information about the status of medications in relation to registration, funding and manufacturers' recommendations. All prescribers must ensure that they are informed of current information about the medications that they use, and should be aware when they are using medications that are 'off-label'. All medications should be used with caution and patients should be carefully monitored while taking medication. Clinicians are expected to prescribe safely and should be knowledgeable about potential interactions. In particular, prescribers need to keep up to date with current literature, especially with newly reported adverse effects, and 'black box' warnings.</p>	C

Part 5: Living in the community

Part 5 identifies the support and transition needs of people with ASD and their families and whānau as they relate to community living. This section focuses mainly on older children, adolescents and adults with ASD.

Transition from high school to further education and/or work (paid and unpaid), and from these activities to retirement, can cause significant stress and anxiety for the person with ASD.

The transition from secondary school into further and post-compulsory education should be carefully planned, with support needs clearly identified. Providers of further education need to have knowledge of the specific educational needs of people with ASD to maximise the opportunity for educational success.

Young people and adults with ASD often experience difficulty securing and maintaining work. The work prospects and experiences of people with ASD improve if their ASD characteristics are considered. Positive work outcomes (eg, increased chances of finding work, maintaining work and having good working relationships) for people with ASD (including those with intellectual disability) are more likely when specialist employment services are involved. These services also can help employers to adopt more positive and flexible attitudes towards their employees with ASD.

For some people with ASD, further education and/or work may not be a goal. For these people, access to meaningful daytime activities and opportunities to participate in recreation and leisure options are important.

Recreation is a powerful tool for promoting independent functioning, community inclusion and proficiency of life skills. Common barriers to participation for people with ASD include negative community attitudes, lack of support, difficulties in communication and low income. Strategies to promote community participation are discussed, together with the particular difficulties in exploring recreation options experienced by children, adolescents and adults with ASD.

It is commonly believed that people with ASD and other disabilities have a higher likelihood of contact with the police, courts and criminal justice system than other people, but there is little real evidence of this. People with disabilities have an increased risk of being victims of crimes, but there is no evidence of an association of people with ASD with criminal behaviour. Given the nature of ASD, young people and adults with ASD are likely to experience difficulties when in contact with the police, courts and the criminal justice system and they need particular support to prevent unintentional victimisation and undermining of legal and criminal justice processes. The guideline provides advice for the person with ASD when having contact with the police, advice for the family and whānau and support persons of young people and adults with ASD when having contact with the police and courts, and ASD-specific knowledge for police, courts and criminal justice personnel.

Key Recommendations for Living in the Community	Grade
1. Careful and timely attention should be paid to planning for people with ASD leaving school and moving into further and post-compulsory education, work (paid or unpaid) or vocational services.	C
2. Providers of further and post-compulsory education should ensure that their members of staff are aware of the specific educational needs of people with ASD.	C
3. Work (paid and unpaid) should be considered an option for all people with ASD, regardless of their intellectual ability. Known support needs of people with ASD who also have an intellectual disability should be considered when transitioning into work. Specialist employment services for people with ASD should be developed.	B
4. Vocational services of a high standard should be available to people with ASD who are not ready or able to access post-compulsory education and work.	B
5. All children and adults with ASD should have access to leisure facilities and meaningful activity tailored to their needs and interests. This is supported by person-centred plans designed by staff who have received specialist education for the role using strategies to promote social inclusion. Plans should be regularly evaluated.	B
6. Leisure and recreation planning should be included in a student/young person's transition programme and this information shared with post-school providers.	C
7. Where a child or young person is provided with a respite service, the environment needs to be structured and predictable. It needs to support the function of the child in communication, personal independence and safe leisure skills.	B
8. People having regular contact with children and young people with ASD should be screened for safety, and paid staff should be appropriately trained, supported and supervised.	C
9. People with ASD should be taught social skills and be educated in community safety, strategies to keep safe when out at night and what to do if they are abused.	C
10. If people with ASD are abused, they should receive services from Child, Youth and Family Services (CYFS), Victim Support, Accident Compensation Corporation (ACC) (Sensitive Claims Unit) and other similar agencies.	C
11. Families, whānau, carers and professionals should ensure that measures are taken during childhood to prevent the characteristics of ASD developing into behaviour that leads to victimisation or criminal offending.	C

Key Recommendations for Living in the Community	Grade
12. Young people and adults with ASD should be taught their legal rights and be prepared in advance with information should they ever have to have contact with the police and legal authorities and appropriate resources and training should be developed to help with this.	C
13. People with ASD involved in disputes within the Family Court should seek support from solicitors and advocacy services with knowledge and experience in ASD.	C

Part 6 Professional learning and development

Part 6 discusses the professional learning and development needs of the many different individuals who interact with and provide services for people with ASD.

Parents, specialists, education, health and other disability professionals and paraprofessionals who work or live with people with ASD can improve the outcomes for those people if they have the necessary skills developed through education. This education will range from awareness-raising to specialised education. Some principles of effective professional learning and development are discussed. It is recommended that professional learning and development in ASD be coordinated nationally, and standards and required competencies be developed.

Key Recommendations for Professional Learning and Development	Grade
1. All professionals who come into contact with children, whether in health care services, early childhood education centres or primary schools should receive training on 'alerting signals' of possible ASD.	C
2. Education and training of local health care professionals in the administration of standardised autism, Asperger syndrome and ASD assessment interviews and schedules should be provided. When reporting the results of ASD-specific tests, caution should be exercised as New Zealand norms have not yet been established.	C
3. Norms should be developed for autism, Asperger syndrome and ASD assessment tools specifically for the New Zealand population.	C
4. Professional education curricula for people working in health, education and social services should include knowledge and awareness of the difficulties partners of those with ASD may experience.	C
5. Social service staff members should have adequate education in child-welfare issues relating to parents who have ASD.	C
6. Professional learning and development should be consistent with evidence and principles of quality provision.	B

Key Recommendations for Professional Learning and Development	Grade
7. Agencies should ensure that members of staff have current and ongoing good quality education in ASD and those agency procedures should incorporate best practice in ASD.	C
8. Different professional groups and multidisciplinary teams should be given the opportunity to train together.	C
9. In addition to workshops and seminars, all professionals and paraprofessionals who are learning new skills should be offered opportunities for practice, coaching and feedback.	C
10. Distance learning opportunities should be developed for those working away from main centres.	C
11. Priority for professional learning and development should be given to those who provide a specialist or consultancy service and support and education to others.	B
12. Identification, education and support of ASD consultant practitioners should be a priority in each region. Consultant practitioners should be skilled in evaluating programmes and translating research into practice.	✓
13. The development of a coordinated national plan for professional learning and development should be undertaken. This should include standards for professional learning and development and competencies for professional roles.	✓

Part 7 Māori perspectives

Part 7 identifies the issues of concern to Māori. A full literature search was done to identify evidence-based information relevant to Māori and ASD. As well, five hui were conducted throughout New Zealand in 2005 to provide an opportunity for Māori to contribute their views and perspectives about ASD. From these hui, a descriptive analysis was done which identified the main issues. Recommendations were then developed based on the findings of the literature review and the main themes from the hui.

Key Recommendations for Māori Perspectives	
1. Information packages in appropriate and relevant language about ASD using a range of media should be developed. This information could be distributed through Māori, mainstream and community providers of health, education and disability services.	✓
2. The appointment of a kaiarahi (guide) who would work with, and be supported by, the health, education and disabilities sectors involved with ASD should be considered.	✓
3. A programme of empirical research that would provide baseline information about Māori and ASD should be developed.	✓

Part 8 Pacific peoples' perspectives

Part 8 identifies the issues of concern to Pacific peoples. A pan-Pacific approach was taken to highlight broad principles, although the diversity of the different Pacific cultures is recognised. Recommendations were developed from public reports, guidelines, published statistics and consultation through a fono.

Key Recommendations for Pacific Peoples' Perspectives	
1. A programme of research that would provide baseline information about ASD and Pacific peoples should be developed.	✓
2. A targeted recruitment and development strategy to support increasing the capacity and competence of the Pacific ASD-related workforce should be developed.	✓
3. A strategy should be developed aimed at improving the cultural competency of the mainstream workforce to acquire knowledge and understanding of Pacific cultural values and world views and appropriately apply this to their work.	✓

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