

New Zealand  
Autism Spectrum Disorder  
Guideline

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Whakapūpūtia mai ō mānuka kia kore ai e whati

Cluster the branches of the mānuka so that they will not break

This revised 2nd edition of the New Zealand Autism Spectrum Disorder Guideline is dedicated to the memory of our colleague and friend, the late Joanna Curzon, who was instrumental in the development of the original guideline and in establishing and supporting the living guideline process.

Haere i muri i te tuarā o Te Whāpuku

We can achieve success by following  
the lead of a person with great mana

## Voices

### People with ASD and their families/whānau

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

“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.”<sup>2</sup>

“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.”<sup>3</sup>

“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.”<sup>4</sup>

“It is not wrong to think in a different way.”<sup>6</sup>

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

“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.”<sup>5</sup>

“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.”<sup>6</sup>

“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.”<sup>5</sup>

“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.”<sup>7</sup>

“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.”<sup>6</sup>

“I am tired of having to do 100% of the changing, and there is no change with most people without autism.”<sup>7</sup>

“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.”<sup>5</sup>

“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.”<sup>6</sup>

“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.”<sup>5</sup>

“I am sick of social skills groups ... Why can't someone go to the bar with me or to chess club?”<sup>10</sup>

“Parents become highly educated – of necessity, not of choice.”<sup>8</sup>

“I have not ‘recovered from autism. I believe that no human being should be ashamed of who he or she is.”<sup>3</sup>

“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.”<sup>7</sup>

“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?”<sup>9</sup>

“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.”<sup>10</sup>

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## Overview

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“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.”

## 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.

### Purpose of the New Zealand Autism Spectrum Disorder Guideline

This guideline is intended 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 the 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 assist informed decision-making to improve the health, educational and social outcomes for individuals with ASD. The guideline is intended for use by primary care practitioners, education professionals, policy makers, funders, parents, carers, specialists and any others who make provision for individuals with ASD.

## About the New Zealand Autism Spectrum Disorder Guideline

### Foreword

The New Zealand Government is proud to launch the 2016 edition of the Autism Spectrum Disorder Guideline. This Guideline is an opportunity to better understand how best to support people with autism spectrum disorder (ASD) and their families. It also provides a framework to improve services for people with ASD, based on robust and reliable information.

The Guideline is the world's first Living Guideline in this area to acknowledge the whole of a person's life – from early intervention and diagnosis, to community living for adults.

Being a Living Guideline means there are regular updates for topics where new, significant research has emerged. Every year since 2009, a topic for update has been identified and the new evidence critically reviewed. This review is then considered by a small advisory panel to inform their revision and development of new recommendations. The 2016 edition of the Guideline incorporates the panel's updated recommendations and the rationale for each of the seven completed update topics.

By regularly updating the guideline it can be more responsive to the needs of the people it has been written for, ensuring it has real meaning to those who use it.

The Guideline has had input from individuals with ASD, parents of children with ASD, medical, educational and community providers, government agencies, and New Zealand and overseas researchers. It represents a ground breaking collaborative effort and a significant achievement by all contributors.

The Ministry of Health's clarification of eligibility for people with ASD has meant that since April 2014 people with ASD have been able to access Disability Support Services. The Ministries of Health and Education have also been working together to ensure that people with ASD and their families receive a coordinated service.

The 2016 edition of the Guideline affirms the Ministries' commitment to having meaningful, contemporary resources to support people with ASD and their families.

We commend the release of this updated edition of the New Zealand ASD Guideline and its goal of improving services to people with ASD and their families.



Hon Hekia Parata  
Minister of Education



Hon Peseta Sam Lotu-liga  
Associate Minister of Health

## Preface

I was born into a rural South Auckland family 60 years ago. I took my first steps at 22 months of age and many sounds terrified me. I refused to touch sticky substances such as buttered toast. I had many other developmental delays and differences but also some above average skills such as reading and writing. Many of these differences were long-lasting and the challenges of adulthood made some of them more noticeable. My collective characteristics were not recognised as a case of Asperger Syndrome (a form of Autism Spectrum Disorder – ASD) until my accidental encounter with an autism specialist when I was forty-three.

New Zealanders should no longer have to experience such scenarios. Because of increasing awareness of ASD, to which this Guideline makes a significant contribution and is a world first, individuals with this different way of thinking can be recognised, supported and valued. Scientific knowledge of the human brain and body is far from complete. Full understanding of Autism Spectrum Disorder (or, if you prefer, “autism spectrum difference”) is still some years away. So the NZ ASD Guideline is a foundation for future ‘living guidelines’. It does not contain everything that is known, or is yet to be discovered, about ASD, but is an excellent introductory one-stop-shop from which interested people can get information and increase their understanding.

I look forward to, and work towards, the day when all individuals who would benefit from an ASD diagnosis can get one; when children and adults with motor skill difficulties are not forced to participate in sports and then laughed at, but are instead helped to improve their basic co-ordination; to a time when professionals in all fields upskill themselves to at least a basic level of Autism-friendliness, and can also admit when they don’t know everything about ASD; and when ASD is not automatically seen as a problem, but is valued for its contribution to a resource pool of people thinking outside the square.

Looking back in time at some unique individuals, it appears that an above average proportion of exceptional achievements have been, and are being, made by individuals with ASD, whether they, or the world, know they are on the autism spectrum.

Information about high-functioning autism (researched in 1943) was not disseminated for 50 years, so many individuals with ASD did not get the diagnosis when they should have, in early childhood. This backlog of people has only recently begun to be correctly diagnosed, thus giving a misleading impression of ASD being both a “new” condition and an epidemic. I believe we have long existed in significant numbers, but our differences have not always been recognised as ASD.

When I told my mother about the ASD Guideline, she said “If only we had had this book when you were growing up.” I offer this resource to my own ever-patient mother; to all other parents and family members of individuals with ASD (both diagnosed and not yet identified); to professional people in all careers; and last but not least, to all of us who have the “autism spectrum difference” ourselves.



Jen Birch  
Adults with ASD



Dave Lennard  
Adults with ASD

## Autism Spectrum Disorder Guideline development process

### Background

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 a number of 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. This led to the establishment of the Autism Services Interdepartmental Working Group (ASIWG) in 1999. The Ministries of Health and Education and the Department of Child, Youth and Family were represented in this group. ASIWG was set up to implement the recommendations of the review and agreed to oversee the development of an ASD Guideline.

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. For the first time in New Zealand, the ASD Guideline was seen as a way of providing evidence-based information for health, disability and education professionals and social service agencies for the provision of services for people with ASD, their families and whānau.

The ASD Cross Government Officials Group was established in July 2004 to replace ASIWG. The purpose of the group was to improve the progress being made in the development of ASD initiatives and to oversee the completion of the ASD Guideline. The Senior Officials also provided regular updates for their respective Ministers.

An ASD Guideline Steering Group was convened in December 2002 to help guide the work of the guideline project team. The purpose of the group was to ensure the perspectives of service users were included in the ASD Guideline, promote awareness of cultural and migrant issues and help build the credibility of the project within the community. The Steering Group members include representation from: adults with ASD; parents/families of people with ASD; the Paediatric Society; 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; Pacific advisors; 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.

The Ministries of Health and Education jointly funded the ASD Guideline. Primarily, this involved funding the work of the three workstreams set up to develop the ASD Guideline. The Paediatric Society of New Zealand led the Assessment and Diagnosis workstream guideline development which was funded through a contract from the Ministry of Health. The Ministry of Education, Special Education (GSE) funded the Education workstream. The Disability Services Directorate in the Ministry of Health funded the Support and Transition workstream.

Work was coordinated by a Project Manager in the Ministry of Health with support from Technical Editors who were independently contracted to carry out specific work. The Project Sponsors were responsible for overseeing this work and allocating the funding in the project.

## 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 alleviated. Part 5 focuses on the support needs of people with ASD within the community setting, covering a variety of aspects from transitioning from secondary school into adulthood to dealing with the criminal justice system. Part 6 focuses on the requirements for professional learning and development 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 originally written in separate sections by three workstreams and 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.

Workstream 1 was led by the Paediatric Society of New Zealand under contract to the Ministry of Health. It addressed assessment and diagnosis in children and pharmacotherapy in children.

Workstream 2 was led by the Ministry of Education and addressed management in the education sector and professional learning and development issues for professionals and parents. Workstream 3 was funded by the Ministry of Health and 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 output from this process has been merged and integrated to provide a coherent approach to management issues. Māori input has been overseen by a Māori Advisory group set up by the Ministries of Health and Education. A series of nationwide hui were undertaken to gain further Māori input. Pacific input has been provided by a fono and the subsequent work of a Pacific researcher. Separate chapters on Māori and Pacific perspectives are provided to guide management of ASD in a culturally appropriate manner.

Separate methodologies were followed by the different contributors to the ASD Guideline. A detailed description of the methods used by the workstreams to develop the guideline is provided in Appendix 1. The process that was followed by the Māori and Pacific peoples' teams is described within their chapters. In brief, Workstream 1 adapted the National Autism Plan for Children 2003<sup>11</sup> developed in the United Kingdom, for New Zealand circumstances to inform the assessment and diagnosis of children in Part 1 of the guideline. The development of all other parts of the guideline has been based on 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).

The workstreams contributed different parts to the merged guideline. The contributions are as follows:

**Part 1:** Workstream 1 (for young children) and Workstream 3 (for young people and adults)

**Part 2:** Workstreams 2 and 3

**Part 3:** Workstream 2

**Part 4:** Workstreams 1 and 3

**Part 5:** Workstream 3

**Part 6:** Workstreams 1, 2 and 3

**Part 7:** Māori Guideline Development Team

**Part 8:** Pacific Peoples' Guideline Development Team

**Appendix 5:** Workstream 1

**Appendix 6:** Workstream 1

**Appendix 7:** Workstream 2

**Appendix 8:** Workstream 2

**Appendix 9:** Workstream 1

The lists of practice questions that were developed to inform the comprehensive searching that was undertaken for this guideline and the evidence tables that formed the basis of the development of recommendations can be accessed on the Ministry of Health website <http://www.health.govt.nz/our-work/disability-services/disability-projects/autism-spectrum-disorder-guideline/supporting-materials-asd-guideline>

Recommendations have been graded according to the system used by the New Zealand Guidelines Group.

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 Team, 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 Team or feedback from consultation within New Zealand.	✓

Further details of the processes that were followed are provided in Appendix 1.

## Living Guideline process

A Living Guideline process was established in 2009. This process ensures that the guideline is regularly updated and refined to reflect new research findings and changing user needs. Updates within the living guideline process are required when the recommendations in the first edition of the guideline are no longer considered valid in view of new evidence.

A small multidisciplinary team form the Living Guideline Group (LGG), an advisory group responsible for identifying topics for update, considering new evidence, and reporting on any implications for guideline recommendations. Membership of the LGG is listed in Appendix 2.

Every year since 2009, a topic within the guideline has been prioritised for update by the Living Guideline Group. A systematic review is undertaken involving the identification and critical appraisal of new research published since 2004, the date that final literature searches were conducted for the guideline's first edition. An assessment of the quality, quantity, consistency, applicability, and clinical impact of all the studies forms the *body of evidence*. This is considered by the LGG at a face-to-face meeting. The wording and evidence grading of relevant current recommendations and good practice points in the guideline are reviewed and revised. New recommendations and good practice points are also developed.

A comprehensive Supplementary Paper describing the systematic review and LGG decisions is prepared for each updated topic.<sup>12–18</sup> These are published annually on the Ministry of Health website ([www.health.govt.nz/our-work/disability-services/disability-projects-and-programmes/autism-spectrum-disorder-guideline/keeping-guideline-date](http://www.health.govt.nz/our-work/disability-services/disability-projects-and-programmes/autism-spectrum-disorder-guideline/keeping-guideline-date)). Revisions from the first seven updates have been incorporated into this new edition of the guideline. Future topic updates will

continue to be made available electronically via the Ministry of Health website.

Marita Broadstock (INSIGHT Research Ltd) prepares the systematic reviews and Supplementary Papers, and directs the living guideline process. The first three updates were undertaken under the oversight of the New Zealand Guidelines Group.

The entire living guideline process is funded by the New Zealand Ministry of Health, and sponsored by the New Zealand Ministry of Education.

## How to read the new edition

The Living Guideline process leads to the development of revised and new recommendations and good practice points for each annual topic update. In this edition of the guideline, revisions for the first seven completed update topics have been incorporated into the tables. New recommendations and good practice points are indicated through the addition of a sub-level to the numbering (eg, new Recommendation 4.3.5a is inserted after existing Recommendation 4.3.5). Summaries for revisions for each update, as well as the Living Guideline Group's rationale and any additional supplementary text, are provided in Appendix 10.

The first edition of this guideline was prescient in recognising the movement toward considering autism as a spectrum condition. In the guideline's title and frequently throughout the text and recommendations, the term Autism Spectrum Disorder (ASD) has been used. This terminology is consistent with the current version of the Diagnostic and Statistical Manual for Mental Disorders, the DSM-5.<sup>18</sup> In the DSM-5, subtype diagnoses of Asperger disorder, Autistic Disorder, Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder –

Not Otherwise Specified (PDD-NOS) are now replaced by the term Autism Spectrum Disorder or ASD.

The implications of the DSM-5 for the guideline were considered by the Living Guideline Group in their Supplementary Paper<sup>16</sup> (summarised in Appendix 10.5). In this edition of the guideline, references to previously used diagnostic subtypes have been retained to reflect their application in research studies, as well as their continued currency in the community. The Living Guideline Group advise that, in view of the DSM-5, where the terms Asperger syndrome and PDD-NOS are used in the Guideline they should be read as referring to ASD.

## Consultation

To finalise the draft of the first edition of the New Zealand Autism Spectrum Disorder Guideline, a four-month written consultation process was undertaken from December 2006 to March 2007. Feedback was sought from across the health, education, disability and social service sectors.

The consultation process involved a mail-out on request of the draft ASD Guideline and a submission booklet. These documents were also available on the Ministry of Health website, with links from the Ministry of Education website. At the same time, an expert peer review process was undertaken with nine international experts in autism spectrum disorder (ASD). The suggestions and references from both processes were analysed to determine whether they provided additional evidence to inform the recommendations of the guideline. Where appropriate, modifications and amendments were made to the draft ASD Guideline. A report on the analysis of 108 submissions received from the open consultation process was provided to all submitters on request. A full list of all individuals and organisations that consented to have their names published is provided in Appendix 3.

A focused consultation process was also conducted for the annual updates as part of the living guideline process. Details are provided within each Living Guideline Group Supplementary Paper.<sup>12–18</sup>

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In addition, the following individuals (in alphabetical order) contributed significantly to the Living Guideline Group (LGG) process and the updating of evidence incorporated into this second edition of the guideline. Full affiliations are provided in Appendix 2.

- Jill Bevan-Brown, Massey University (retired) (LGG member)
- Tanya Breen (LGG member)
- Marita Broadstock, INSIGHT Research Ltd (LGG Project manager and lead researcher)
- Sally Clendon, Massey University (LGG member)
- Joanna Curzon, Ministry of Education (past LGG ex-officio)
- Elizabeth Doell, Massey University (past LGG member, past LGG ex-officio)
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Marita Broadstock, INSIGHT Research, was also technical editor responsible for incorporating the Living Guideline updates into the second edition.

### **Declaration of competing interests**

Contributors to the ASD Guideline were asked to declare any competing interests. There were no competing interests declared by any contributors to the ASD Guideline.

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## 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, it has been the subject of intense research and a great deal is now known about how to ameliorate the disorder, although there is no known 'cure'.

This 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

The term ASD is used to refer to a condition that affects communication, social interaction and adaptive behaviour functioning. In the DSM-5<sup>18</sup> four pervasive developmental disorder subcategories specified in the diagnostic manual's predecessor, the DSM-IV,<sup>21</sup> are now subsumed into one broad category of autism spectrum disorder. These subtypes were autistic disorder, Asperger's disorder (Asperger syndrome), childhood disintegrative disorder (CDD), and pervasive developmental disorder not otherwise specified (PDD-NOS). The name pervasive developmental disorder (PDD) has now been changed to Autism Spectrum Disorder (ASD), the term used throughout this guideline (*see Appendix 4 and Appendix 10.5 for details on diagnostic criteria and changes made under DSM-5*).

The spectrum of autism disorders is now recognised as covering a wide range of severity and intellectual ability.

Those diagnosed with ASD all display (or have in their lifetimes displayed):

- impairment in social communication and social interaction
- restricted, repetitive patterns of behaviour, interests, or activities.

These are all-encompassing features which cause clinically significant impairment in social, occupational, or other important areas of current functioning, although their intensity may vary.

## Part 1: Diagnosis and initial assessment of ASD

Part 1 of this 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 responsive to alerting signals of possible ASD and be receptive to parental concerns about their children.

Professional 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 in 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 undertaken sensitively, giving the person ample time to ask questions, to understand what is being said and to voice concerns.

Families, whānau and support people may need to be involved in diagnosis disclosure, 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. This results in an identification of needs and a plan of action to meet the identified 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 currently 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 fully consider other possible diagnoses (such as the differential diagnosis).

Clinical judgment may be aided by the use of assessment tools, checklists and rating scales. Suggestions for diagnostic tools and the role of cognitive assessment in individuals with ASD are found in Appendices 5 and 6. However, the applicability of diagnostic and assessment tools to a New Zealand population has not been established and research is required 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"> <li>a. comprehensive developmental surveillance of all children so that deviations from normal development are recognised early</li> <li>b. valuing and addressing parental concerns about their child's development</li> <li>c. prompt access to diagnostic services.</li> </ul>	B
2.	All District Health Boards (DHBs) should have in place processes that ensure: <ul style="list-style-type: none"> <li>a. referral pathways for children and adults who may have ASD or another developmental problem are clearly understood by professionals</li> <li>b. services are coordinated within and across sectors</li> <li>c. multidisciplinary, multiagency assessments are provided</li> <li>d. all services are provided in a timely manner.</li> </ul>	C
3.	All children suspected of having ASD or another developmental problem should have an audiology assessment.	✓
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. In the absence of 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
5.1	Standardised ASD assessment interviews and schedules should be used. The intellectual, adaptive and cognitive skills associated with ASD should be seriously considered and, where possible and appropriate, formally assessed ( <i>see Appendix 10.5</i> ).	B
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 people who share their lives with individuals 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 and whānau 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. Advocacy, rural and cultural issues are also discussed. Provision of information on ASD is seen as crucial by parents and families. It should take a variety of forms and take into consideration 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, families and whānau.

The health care needs of a person with ASD can be complex and the appropriate management of these needs is exacerbated by the symptoms of ASD itself. Specific health care needs, such as poor dental hygiene, sleep disturbance, gastrointestinal symptoms, 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 ceases 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. Thus, some people with ASD need support to manage their physical wellbeing appropriately, and health care professionals require knowledge of ASD and how it affects their clients to be able to provide optimum health care services.

Since ASD is a heterogeneous 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, whānau and carers		Grade
1.	The values, knowledge, preferences and cultural perspectives of the family and whānau 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



Key recommendations for support for individuals, families, whānau and carers		Grade
4.	A key service to support families and whānau is the provision of 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 require assistance to manage their physical wellbeing and health care.	C
6.	Medical and health care practitioners should take into account 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 contention that this vaccine has a role in the causation of 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 required. It is unlikely that 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 looks in detail at a number of 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/whānau. 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's 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 component, other interventions with a different focus may also be required to manage these particular difficulties in people with ASD.

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. Problem minimisation and avoidance early in life is essential. Long-term difficulties may arise if the communicative, social and ritualistic/obsessive aspects of ASD are not attended to.

The first step in treatment of behavioural, emotional and mental health problems is comprehensive assessment which takes into account the family, whānau, social and cultural context. Components of comprehensive treatment plans include those 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 additional 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. Clinicians prescribing these drugs need to keep up to date with current literature.

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, teach skills for independent living, and minimise stress for 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
4.1	Facilitated and structured social skills groups should be considered for high functioning children and young people with ASD ( <i>see Appendix 10.6</i> ).	B
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
5.1	Interventions and strategies based on applied behaviour analysis (ABA) principles should be considered for all children with ASD ( <i>see Appendix 10.1</i> ).	A
5.2	Early intensive behavioural intervention (EIBI) should be considered as a treatment of value for young children with ASD to improve outcomes such as cognitive ability, language skills, and adaptive behaviour ( <i>see Appendix 10.1</i> ).	B
6.	The feasibility of establishing publicly funded, ASD-specific behavioural services should be investigated.	C
7.	SSRIs (eg, fluoxetine) may be effective for some children with ASD and high anxiety and/or obsessive symptoms. However, in the absence of quality evidence, these drugs should be used with caution and careful monitoring. There is insufficient evidence to make any recommendation in relation to 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, depression, and gastrointestinal problems ( <i>see Appendix 10.4</i> ).	C
11.	In severe or life-threatening situations, medication may be the optimum therapy.	C

Key recommendations for treatment and management of ASD	Grade
<p><b>IMPORTANT NOTE FOR PRESCRIBERS:</b></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 in relation to 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 in relation to 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 is mostly focused 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 (both as strengths and as support needs) and cognitive ability are taken into account. 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 best practice supported employment services are involved. These services can also 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 require particular support needs to prevent inadvertent 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. Any known support needs of people with ASD, including cognitive ability, should be taken into account when transitioning into any work environment. Supported employment services for people with ASD should be developed ( <i>see Appendix 10.3</i> ).	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, 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, and 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

Key recommendations for living in the community		Grade
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 (CYF), 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 undertaken during the childhood of the person with ASD to prevent the characteristics of ASD developing into behaviour that leads to victimisation or criminal offending.	C
12.	Young people and adults with ASD should be taught their legal rights, and be prepared in advance with information should they ever have contact with the police and legal authorities. Appropriate resources and training should be developed to assist with this.	C
13.	People with ASD involved in disputes within the Family Court are advised to seek assistance 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 individuals with ASD can improve the outcomes for those individuals 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



Key recommendations for professional learning and development		Grade
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
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 undertaken to identify evidence-based information relevant to Māori and ASD. As a complement to this, 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 identifying the main issues raised was undertaken. Recommendations were then developed on the basis of 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 in conjunction with, and be supported across, 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 is taken to highlight broad principles, although the cultural diversity of Pacific cultures is acknowledged. 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 regarding ASD and Pacific peoples should be developed.	✓
2.	A targeted recruitment and development strategy to support increasing the capacity and capability 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.	✓

## Introduction

### Background

People with autism spectrum disorder (ASD) have often remained undiagnosed and unsupported in New Zealand communities. However, there is an increasing awareness of ASD among health, education and social service professionals, parents and the general public. A nationally consistent standard of practice for the assessment, diagnosis and management of children, young people and adults with this condition should improve access to health, education and social service professionals.

### Definition

Autism Spectrum Disorder (ASD) is a condition that affects communication, social interaction and adaptive behaviour functioning. As specified in the current version of the Diagnostic and Statistical Manual for Mental Disorders, the DSM-5,<sup>18</sup> all people who are diagnosed with ASD share characteristics in two domains: impairment in social communication or social reciprocity, and impairment in restricted, repetitive patterns of behaviour.

Although these features are characteristic of all people with ASD, it is a very heterogeneous condition affecting a very diverse group of individuals with a wide range of severity, disability and intellectual function. The diverse support needs expressed by people across the autism spectrum require that a wide range of services and approaches be employed.

In the latest edition of the diagnostic manual DSM-5,<sup>18</sup> four pervasive developmental disorder subcategories (specified in the manual's predecessor, the DSM-IV)<sup>21</sup> were subsumed into one broad category of autism spectrum disorder. The subsumed subtypes were autistic disorder, Asperger's disorder (Asperger syndrome),

childhood disintegrative disorder (CDD), and pervasive developmental disorder not otherwise specified (PDD-NOS). The name pervasive developmental disorder (PDD) has been changed to Autism Spectrum Disorder (ASD).

The term ASD is used widely internationally and this guideline's first edition was prescient in recognising the movement toward considering autism as a spectrum condition. Increasingly people in the autism community prefer to use identify-first language to refer to themselves as being autistic, autists or Aspies. This recognises autism as a central part of their identity, rather than being a person "with autism". Others prefer to describe themselves as being on the spectrum, or as having autism or Asperger's. ASD is sometimes defined as autism spectrum *difference* rather than *disorder*. In the UK, the term Autism Spectrum Condition (ASC) is gaining favour as an official term instead of ASD. For clarity and consistency with the first edition of the guideline, the acronym ASD is retained in this edition to capture all of these varied terms for autism. However it is recognised that autistics have the right to self-refer and be referred to as they choose.

It is understood that the terms "high functioning" and "low functioning" to describe groups of people with ASD is considered unhelpful and divisive by many on the autism spectrum. In this guideline, the term "high functioning" has sometimes been used (when citing research) to define people with higher cognitive functioning either as established by intelligence tests (generally indicated by full IQ scores of 70 or above), or through the diagnosis of "high-functioning autism" or Asperger syndrome (under DSM-IV criteria). It is acknowledged that these distinctions may no longer be used clinically in light of the removal of Asperger syndrome as a separate diagnostic classification in DSM-5.<sup>18</sup>

## Prevalence

There is no definitive information on the prevalence and incidence of ASD in New Zealand. Recent data (2006) from the United Kingdom reported a total prevalence of all ASDs of 116.1 per 10,000 children, with a prevalence of autism of 38.9 per 10,000 children.<sup>22</sup> Boys are affected about four times more frequently than girls.<sup>23</sup> There is a wide range of prevalence estimates which points to the need for earlier and more accurate identification of the symptoms of ASD. The earlier the disorder is diagnosed, the sooner the child can be helped with interventions. There is evidence from overseas studies that many children with significant ASD are not being identified until after they start school.<sup>24</sup>

Generalising these prevalence data across the whole population of 4 million means that it is estimated there are more than 40,000 individuals in New Zealand who have ASD, although many adults may not have received a diagnosis. Considering the impact on families and others in contact with these individuals, ASD represents a significant health, educational and social issue in New Zealand that needs addressing with adequate service provision.

There are currently international indications that the incidence of ASD may be rising. It is not clear whether this change is due to an actual increase in incidence, or to increased awareness, or to changes in interpretation of the diagnostic criteria. There is ongoing research into autism incidence, prevalence and the reasons for these changes. In planning services, the figures quoted in this guideline should be regarded as conservative.

## Scope

This guideline addresses all aspects of ASD, including diagnosis and assessment, educational provision and other interventions and services that provide

support for individuals and their families and whānau. The recommendations are based on the best evidence currently available, with the broad purpose of assisting informed decision-making to improve the health, educational and social outcomes for individuals with ASD. Throughout the ASD Guideline, the emphasis is on services being provided in a way that focuses on the needs of the child or adult in a family-centred context. The scope of the guideline is comprehensive and no international guideline has been found with such a broad scope. The breadth of this guideline has required an intersectoral approach to development to ensure that health, educational, social and all other relevant aspects are considered.

## Impact analysis

An impact analysis has been funded by the Ministries of Health and Education. The primary purpose is to assess the likely impact of implementing the key recommendations in the guideline, which in turn will assist government decisions regarding its implementation.

To achieve this, the impact analysis used objective and prospective analysis, identified and prioritised the recommendations at a thematic level, and acknowledged the challenges for consideration in planning implementation. More specifically, the impact analysis involved the following:

- a survey of current service provision, supplemented with interviews and focus group meetings
- identification of gaps in services and changes that would be required for implementation
- an outline of legislation and policy implications
- a thematic analysis of actions required to implement key recommendations.

The findings of the impact analysis contribute to the plan for implementing the NZ ASD Guideline.

## Legislation

This is a list of legislation, standards and policies relevant in the New Zealand context that will impact on the Guideline.

### Relevant health, disability and education legislation and policies

#### Legislation and standards

- Human Rights Act 1993
- New Zealand Bill of Rights Act 1990
- New Zealand Public Health and Disability Act 2000
- Health and Disability Services (Safety) Act 2001
- Health Practitioners Competence Assurance Act 2003
- Health Act 1956
- Public Finance Act 1989
- Public Audit Act 2001
- State Sector Act 1988
- Education Act 1989
- Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003
- Health and Disability Commissioner Act 1994
- Code of Health and Disability Consumers' Rights 1996
- Children, Young Persons and Their Families Act 1989
- Criminal Procedure (Mentally Impaired Persons) Act 2003
- The Mental Health (Compulsory Assessment and Treatment) Act 1992
- National Mental Health standard

- United Nations Convention for the Rights of Persons with Disabilities 2008.

#### Policies

- Ministry of Health – Statement of Intent
- New Zealand Health Strategy
- New Zealand Disability Strategy
- He Korowai Oranga – Māori Health Strategy
- Blueprint for Mental Health Services in New Zealand
- Child Health Strategy
- Primary Care Health Strategy
- Te Tahuhu, Improving Mental Health 2005–2015

#### Reports

- Curry Report 1998
- Werry Report 1998
- Māori Disability Action Plan 2004
- Pacific Health and Disability Action Plan
- New Zealand Disability Strategy Implementation Work Plan 2004/5
- Living with Disability New Zealand 2001 Post Census Disability Survey.

## Implementation

Improvement in outcomes for individuals with ASD will only occur with the implementation of the evidence-based recommendations in this guideline. Support and incentives will also need to be built into the implementation strategy. Barriers to implementation, identified in the impact analysis, will provide input for the design of strategies for successful implementation.



# Part 1

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Diagnosis and initial assessment of ASD

“My son is autistic.  
He struggles to  
communicate.”

## Part 1 Diagnosis and initial assessment of ASD

This section of the ASD Guideline covers the principles of identification, diagnosis and initial assessment of individuals with ASD.

The earlier the diagnosis of ASD is made, the more impact early intervention has, resulting in fewer challenging behaviours and better outcomes for families.<sup>25</sup> For the purposes of assessment and diagnosis in children, this guideline divides the population of children into three age groups, according to developmental stage and most likely mode of presentation to services.

- Ages 1 to 3 years – children who present at this age usually have significant language delay and behavioural issues. Referral is usually to a paediatrician, a child development service or specialised early intervention service provider.
- Ages 4 to 8 years – children who present at this age may have milder symptoms of autism spectrum disorder or may have been missed for earlier diagnosis.
- Greater than eight years – children who present at this age usually present to Child, Adolescent and Family Mental Health Services with emotional or behavioural issues. Alternatively, they may present with school performance difficulties to Special Education Needs Coordinators (SENCOs), Resource Teachers of Learning and Behaviour (RTLBs), Ministry of Education, Special Education or paediatricians. Occasionally, they may present via the courts.

Although early intervention may have been undertaken because of concerns about learning and development, most children require a diagnosis to access appropriate management modalities and support services, and to assist the family/whānau with appropriate information to plan their lives. It is therefore essential to diagnose those children with an autism spectrum

disorder early in order to provide early intervention and family/whānau support. International research demonstrates improved cognitive and functional outcomes for children who were diagnosed at younger ages and who then received appropriate early intervention educational support.<sup>25</sup> Experienced clinicians are able to make the diagnosis in children with moderate to severe ASD by the age of two or three years. The children with less severe ASD may not come to attention until they are at early childhood education services or at school. These children tend to have better language skills but can still have significant needs.

Much of the literature on ASD centres on the early diagnosis and early intervention of young children with ASD. However, there are also undiagnosed young people and adults with ASD. Some seem to manage well<sup>26 27</sup> while other undiagnosed people and their families endure great stress, and they can be misunderstood, blamed, teased, bullied, poorly supported and miss out on effective treatment options,<sup>28</sup> or receive inappropriate medical, psychiatric and educational interventions. Some receive psychiatric or intellectual disability services or both, yet without the recognition of their ASD, services are not appropriately tailored to their individual needs (*see section 4.8: Mental health, forensic and disability services*). For some individuals who have not received an ASD diagnosis, their behaviour may lead to legal difficulties. Should their difficulties not be appropriately identified and taken into account as a mitigating factor, an inappropriate custodial sentence may result (*see section 5.3: Contact with the justice system*).



ASD advocacy agencies,<sup>29 30</sup> professionals<sup>26 28 31 32</sup> and published accounts by people with ASD<sup>33 34</sup> suggest that the assessment and diagnosis of young people and adults with ASD is important because it:

- prevents or rectifies misdiagnosis
- assists in the identification of appropriate educational options and placements
- assists in vocational choice, and identifies support which may facilitate vocational success
- provides access to appropriate resources, support and assistance
- enables appropriate environmental support
- facilitates contact with other people with ASD
- assists in the identification of support needs of families and whānau
- helps people with ASD to understand themselves
- helps people with ASD to understand other people
- helps other people to understand the person with ASD, including families, whānau, partners and employers
- prevents future problems
- minimises isolation by providing access to the ASD community
- may lead to the identification of the broader phenotype of ASD in family members.

Formal criteria for the identification and diagnosis of people with ASD are provided in Appendix 4 with respect to the fourth edition of the Diagnostic and Statistical Manual for Mental Disorders (DSM-IV-TR). These criteria were revised in the latest version, the DSM-5<sup>18</sup>. Implications of these changes for the guideline were considered by the Living Guideline Group and are summarised in Appendix 10.5.

## 1.1 Identification and diagnosis

### Summary of recommendations

Recommendations:		Grade
1.1.1	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.	B
1.1.2	A formal whole population screening programme for the identification of ASD is not recommended.	B
1.1.3	Health and education professionals should take regular opportunities (at least at 8–12 months, 2–3 years and 4–5 years) to discuss the child's development with parents as part of 'surveillance' to detect and respond rapidly to any developmental concerns.	C
1.1.4	Age of detection/diagnosis of all developmental problems, including ASD as a specified disorder, should be audited.	C
1.1.5	Parental inquiries regarding developmental concerns about their child must be taken seriously and addressed appropriately.	B

Good Practice Points:	
1.1.6	At each health or educational professional encounter, concerns should be elicited regarding child development. ✓
1.1.7	All health and education professionals involved in care of children should know referral pathways for those children about whom concerns are raised. ✓

The benefits of the early identification of children with ASD are well recognised by parents and professionals (*Recommendation 1.1.1*). Identification of some health conditions is undertaken by 'screening', which is defined as the formal identification of a previously unrecognised disease or condition by the application of tests, examinations or other procedures that can be applied to a whole population. However, the United Kingdom National Autism Plan for Children (NAPC) review of the literature found no supporting evidence for implementation of a population-screening tool for identification of people with ASD<sup>11</sup> (*Recommendation 1.1.2*). Their findings supported the consensus that

parents or professionals with knowledge of normal development can identify ASD. Early identification of ASD can only take place with regular developmental surveillance by parents and/or health and early education professionals.

### 1.1.a Early childhood

#### Early surveillance

The Tamariki Ora Schedule currently includes developmental surveillance which is undertaken at all contacts with a Well Child nurse.<sup>35</sup> Developmental surveillance is a shared parent–health professional activity which uses both parties’ knowledge about the child to monitor the child’s ongoing development. On occasions, the surveillance process may identify children whose developmental progress varies significantly from the expected pathway.

Regular surveillance enables early identification of areas of developmental concern.

To facilitate early identification of children with ASD, best practice in New Zealand requires adherence to procedures currently employed by health care practitioners:

- proactive monitoring, or surveillance, for developmental milestones at all Well Child visits
- eliciting parental or carer concerns about development and behaviour at each contact with a health care (or education) professional (as recommended in the Well Child Handbook).<sup>35</sup> This requires that all professional encounters with young children, including contacts with daycare providers and early childhood teachers, should be viewed as opportunities to elicit developmental information and concerns (*Recommendations 1.1.3 and 1.1.4, Good Practice Point 1.1.6 and 6.1 Professional learning and development*).

Although many parents are aware by 18 months that their child is different, formal diagnosis of autism has often been delayed in the past.<sup>36</sup> Retrospective surveys in the United Kingdom have indicated that

60% of parents report that they were first to suspect a problem, compared with 10% who remembered that it was the health visitor, while for 7% it was the school staff who first acknowledged concern.<sup>37</sup>

Although<sup>37</sup> skilled community health and education staff can assist parents in the recognition of a problem, many parents comment that the response of professionals to their expressed concerns was to either offer inappropriate reassurance or give the impression that the parents were being ‘over anxious’. Although similar information is unavailable in New Zealand, the experience of those working in the area of ASD suggests that the situation is likely to be no different.

Studies<sup>38–40</sup> show that a valid clinical diagnosis can often be made by the time the child is aged 2 to 3 years. However, diagnosis is more difficult in young children who are more able, and in those with significant general developmental delay (eg, a mental age below one year).

The opinion of the committee which developed the NAPC in the United Kingdom, supported by experience in New Zealand, is that there have been a number of barriers to early diagnosis.<sup>41</sup> These include: failure to recognise symptoms, denial that there may be a problem, failure to get a referral, lengthy waiting time for an appointment, inadequately trained staff for diagnosis and separate waiting lists for each professional group.

Successful identification of ASD in young children and the effectiveness of intervention programmes are dependent on the ability of primary care providers to monitor children’s development and initiate referrals in a timely manner. Well Child nurses, general practitioners (GPs) and other members of the primary health care team are therefore central to early identification. Consequently, the importance of primary care practitioners cannot be overemphasised. This has

implications for the education of primary care health providers. Indeed, all professionals who come into contact with children, whether in health care services, early childhood education centres or primary schools, should receive training in ‘alerting signals’ of possible ASD (*Recommendation 6.1, Professional learning and development*).

### **Eliciting, valuing and addressing parental concerns**

Parents of children with ASD often note features that were markedly different during the child’s first two years of life. Since parents are experts about their children, eliciting and valuing parental concerns is imperative. Studies have shown that when parents raise developmental concerns, some primary care practitioners respond either by waiting to see if the delays will resolve spontaneously or by discounting parental observations.<sup>41</sup> While a small number of children do ‘catch up’ without formal intervention, this approach will delay identification and treatment of children with ASD who could substantially benefit from earlier identification and treatment (*Recommendation 1.1.5*).

### **Assuring appropriate referral of a child with possible ASD**

Throughout New Zealand there is no consistent referral and assessment pathway for children with ASD (or indeed children with other developmental problems). Multiple potential referral points exist, such as Child Development Services or Ministry of Education, Special Education, but there is no single service with the designated overall responsibility for coordinating assessments. This leads to confusion amongst parents and primary health care providers about what to do

when a child is identified as showing some autistic features (*Good Practice Point 1.1.7*).

There are genetic factors in the causation of autism, but as yet there is limited information on how these genetic factors work and even more limited information on potential gene–environment interactions. There are a small number of single gene disorders which are associated with autistic symptoms. These include fragile X, Rett syndrome and tuberose sclerosis. Evaluation for genetic disorders is outside the scope of this guideline. Clinicians should consider the possibility and importance of genetic factors for each individual and carry out appropriate investigations, as indicated by clinical assessment. Clinicians should provide genetic advice where indicated and ensure onward referral, where necessary.

### **Children aged 1 to 3 years**

In the first year of life, there are usually no clear discriminating features<sup>42</sup> and delays/impairments in development may not necessarily be recognised by either parents or professionals. Any parental concerns around the infant’s development or the way the infant responds need to be acknowledged by professionals and discussed fully with the parents. At this age, initial discussion is likely to be with a primary care health professional, but may also be with an early childhood education provider. Some children between the ages of 13–23 months may lose developmental skills. As an example, it may be reported that they stop using words, lose eye contact and regress in relation to social skills.

The following table gives information on key signs which should indicate referral for children aged 1 to 3 years.

Table 1.1: Key signs for identification of children 1–3 years with ASD	C
<p>All children with ANY of the following findings MUST be referred for a general developmental assessment:</p> <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<sup>43</sup></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.<sup>44 45</sup></li> </ul>	
<p><b>Key signs in children aged 1–3 years</b> (which should prompt referral for a developmental assessment (modified from the NAPC Guideline)):<sup>11 40</sup></p> <p><b>Social impairments:</b></p> <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 to share interest or 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> <p><b>Communication impairments:</b></p> <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>	

Table 1.1: Key signs for identification of children 1–3 years with ASD	C
<p><b>Impairment of interests, activities and other behaviours:</b></p> <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, cooperative 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> <p><b>Other factors which may support a diagnosis of ASD:</b></p> <ul style="list-style-type: none"> <li>• Over- or under-sensitivity to: <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> </li> </ul> <p><b>Note:</b> These factors in isolation are not indicative of ASD. They are intended to alert professionals to think about the possibility of ASD – whether and when they make a referral will depend on the overall situation.</p>	

### Children aged 4 to 8 years

Professional concerns about more able children with ASD may not develop until children are exposed to the greater social demands of the early childhood education service or primary school environment. Indeed, prior to school entry, some may have been thought to be well advanced in their development, because of their special interests and precocious vocabulary.

The following features should alert teachers and others to the possibility of ASD. The features described for younger children are also applicable to this age group. Presence of these features should trigger discussion with parents and the possible implementation of the local referral pathway.

Table 1.2: Key signs in children aged 4–8 years with ASD (modified from the NAPC Guideline) <sup>11</sup>	C
<p><b>1. Communication impairments:</b></p> <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> <p><b>2. Social impairments:</b></p> <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 cooperate in classroom activities; inability to appreciate/follow current trends, eg, with regard to other children’s dress, style of speech, interests etc)</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> <p><b>3. Impairment of interests, activities and behaviours:</b></p> <ul style="list-style-type: none"> <li>• lack of flexible, cooperative 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>	

Table 1.2: Key signs in children aged 4–8 years with ASD (modified from the NAPC Guideline) <sup>11</sup>	C
<p><b>4. Other factors which may support a diagnosis of ASD:</b></p> <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>	

No criteria were provided in the NAPC Guideline to guide referral for diagnosis in children older than eight years. Guidance for diagnosis of older children can be found in the next section.

### 1.1.b Young people and adults

Four factors that commonly prompt initial referral for diagnosis of children beyond childhood include:<sup>41 46</sup>

- symptom changes and diagnostic dilemmas – where children formerly diagnosed with conditions such as PDD-NOS have matured, their behavioural and emotional characteristics have altered, and, consequently, the original diagnosis is being re-evaluated
- social deficits – where the differences in social behaviour between the person in question and same-age peers has become more obvious
- difficulty meeting academic expectations – where the child's response to the increasing demands of the educational system is of concern
- considerations such as family, whānau, cultural, community, or other demographic factors that mediate the dysfunctional quality of behaviours – where factors formerly suspected to account for the child's behavioural characteristics hold less weight.

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



## 1.2 Assessment

This section describes the process that should take place from the identification of a concern that an individual has a problem that may be an autism spectrum disorder through to making a diagnosis.

### Summary of recommendations

Recommendations:	Grade
1.2.1 The initial assessment of children may be undertaken by an individual practitioner. If there are ongoing concerns, a multidisciplinary assessment is recommended.	B
1.2.2 Preferably, a multidisciplinary team of health care practitioners experienced in ASD should undertake diagnostic assessment of young people and adults suspected of having ASD. In the absence of an assessment team, a health care practitioner trained and highly experienced in ASD may undertake diagnostic assessment.	B
1.2.3 Formal pathways for diagnostic assessment of young people and adults should be developed.	C
1.2.4 Diagnostic assessment of young people and adults should be comprehensive (covering all areas listed below), and involve the person concerned in interview and observation ( <i>see Appendix 10.5</i> ).	C
1.2.5 Standardised ASD assessment interviews and schedules should be used ( <i>see Appendix 10.5</i> ).	B
1.2.6 Test users should ensure that they are aware of the validity, reliability and appropriateness of tests when assessing people with ASD and take these limitations into account when forming opinions and reporting results.	C
1.2.7 The intellectual, adaptive and cognitive skills associated with ASD should be seriously considered and, where possible and appropriate, formally assessed.	B

Good Practice Points:		
1.2.8	Children identified with a significant developmental concern in the 0–7 year age group should be seen by a developmental or general paediatrician.	✓
1.2.9	A developmental services coordinator should be appointed in each local area. This person would manage the referral process for all children about whom there are developmental concerns.	✓
1.2.10	All children suspected of having ASD or another developmental problem should have an audiology assessment.	✓
1.2.11	If the general developmental assessment suggests an autism spectrum disorder, the developmental services coordinator should arrange a multidisciplinary assessment of the child.	✓
1.2.12	Where the local Specialist Assessment Team has found difficulty in making a diagnosis because of atypical or complex presentation, a network of tertiary centres should be provided where children could have a tertiary-level assessment.	✓
1.2.13	The psychometric properties of formal ASD assessment tools within the New Zealand population should be further researched.	✓
1.2.14	Assessment should consider the influence of diversity such as sense of self, ethnicity, culture, gender, sexuality, religion, socio-economic status, and geographic factors.	✓
1.2.15	Assessment of an individual should elicit and consider whether that person requires, would value, and would benefit from a diagnosis of ASD.	✓

Assessment is the process undertaken by gathering information about the health, education and care needs of a person and family/whānau. This results in an identification of needs (including diagnosis, where appropriate) and a plan for action to meet the identified needs.

As ASD is a developmental disorder, the presentation will vary with age and, in any one individual, vary over time. The characteristics of ASD may be more prominent at some ages than others. A clear understanding of normal social, behavioural and language development is required among parents, carers and professionals.<sup>11</sup>

The assessment has three specific aims:

- to identify health needs of the child (or adult), including consideration of differential diagnosis, establishing aetiology and provision of genetic advice
- to promote understanding and agreement about the potential developmental implications of the condition so that effective educational, behavioural, physical, emotional, social and communication strategies can be put in place to promote development
- to address the needs of the child (or adult) in the family context such that the family is given confidence to provide for the health, learning and care needs of their child or dependant adult, whilst understanding that their own needs (including cultural and spiritual needs) are being taken into account.

From knowledge of current practices and services within New Zealand, there is currently inconsistent and inequitable access to assessment.<sup>9</sup>

### 1.2.a Early childhood to adolescence

The recommended pathway leading to the assessment of a young child, older child or adolescent with suspected ASD is summarised below in four steps:

1. developmental surveillance
2. identification of developmental concerns and appropriate referral
3. appropriate referral and developmental service coordination
4. multidisciplinary assessment.

This pathway is outlined in Figure 1 which can be found at the end of this section.

#### 1. Developmental surveillance

All children in New Zealand should receive developmental surveillance. For babies and children in the early childhood years, this is provided through the Well Child/Tamariki Ora framework. Children and teenagers attending compulsory sector education have educational attainment and behaviour reviewed regularly at school, with schools being required to formally report to parents at least twice per year. Where schools have a particular concern about a student's health, they can consult with the Public Health Nurse linked to the school.

Parents and a range of health and educational professionals (such as Plunket nurses and other Well Child providers, general practitioners (GPs), early childhood educators, playgroup supervisors and teachers) have considerable skill and experience in understanding the pattern of normal child development and should, in the course of developmental surveillance, identify areas of developmental concern. If any concerns become apparent to parents or professionals, these concerns should be discussed immediately.

This discussion between parent and health or educational professional should seek to define the developmental concerns and gather further information about the child's

developmental milestones, unusual social interactions or behaviour, the child's general health, eating and sleeping patterns, and potential family/whānau and environmental impacts on development, such as family emotional or financial stress. Such discussions may be formal (eg, a speech-language therapy screening assessment) or informal (eg, a discussion between a parent and a kindergarten teacher). These are not formal diagnostic assessments.

Health and education professionals should be proactive and should view each professional encounter as an opportunity to elicit developmental, health and social concerns about the child, rather than waiting for parents to voice concern. Routine professional encounters include each Well Child assessment, GP visits for intercurrent illness, and sessions at creche, kindergarten, playgroup or school (*Recommendation 1.2.1*).

A wait-and-see approach, or a desire not to mention a concern for fear of creating unnecessary anxiety in parents, should be resisted, as this could lead to a delay in providing appropriate assessment and other services.

#### 2. Developmental concerns

If the outcome of the discussion between the parent and professional is that developmental concerns are unclear, or if that professional is not formally trained in assessing developmental skills, the professional should seek further advice, guidance or assessment from another professional with expertise in assessing child development. These professionals could include a speech-language therapist, a child development service therapist, or a paediatrician (*Good Practice Point 1.2.8*).

If developmental concerns are confirmed during the discussion between the parent and professional, then onward referral for appropriate assessment must be made, through the developmental services coordinator.

### 3. Developmental and ASD service coordination

A developmental services coordinator (DSC) appointed by the District Health Board (DHB) should be located in each local area (*Good Practice Point 1.2.9*). The DSC should have a clinical background in child development and work closely with health and education services. The DSC should have access to advice from child development services, child and adolescent mental health services, paediatricians and education services including Ministry of Education, Special Education and Resource Teachers: Learning and Behaviour (RTLb). It will be essential for the DSC to have access to advice from a paediatrician, as occasionally, developmental concerns can indicate serious underlying medical problems which need timely assessment.

The role of the developmental services coordinator is to collect more information, ensure that assessment occurs in a timely manner and to support the family/whānau through the assessment process. The coordinator arranges onward referral to appropriate agencies.

- If a medical problem has been identified, referral is recommended to a GP initially and then to a paediatrician, if required.
- If a developmental concern is recognised, referral to the local child-development service, or to Ministry of Education, Special Education is recommended, depending on the type of concern and local referral patterns. Referral to a paediatrician may also be indicated.
- If concerns appear to involve significant emotional, behavioural or mental health issues, referral to an appropriate service according to locally agreed pathways should be considered. This may be the local Child, Adolescent and Family Mental Health Service or

another appropriate counselling, support or service agency.

The role of the developmental services coordinator will include:

- taking enquiries from families and professionals
- gathering information
- coordinating a response, including arranging a general developmental assessment for all children under six years who meet the criteria for significant developmental concern. The general developmental assessment will usually be carried out by a developmental paediatrician or general paediatrician.
- coordinating a response for all children greater than six years of age who meet the criteria for significant developmental concern and, on occasions, for any child or young person attending any compulsory education sector facility.

Referral of the child may include:

- onward referral to a paediatrician, and/or
- onward referral to a specialist service or agency such as:
  - District Health Board child development service
  - Ministry of Education, Special Education
  - other specialised early intervention provider
  - Child and Adolescent Mental Health Services
  - non-governmental organisation (NGO) provider (eg, Family Works, Barnardos)
  - referral to a GP for primary care health assessment/review

- referral for audiology assessment for all children less than six years old where there is any concern about language development.

Hearing evaluation is mandatory in any child with developmental delay in language acquisition (*Good Practice Point 1.2.10*). Children require excellent hearing to develop language. Even mild to moderate hearing loss can lead to problems with language development.

Where the general developmental assessment suggests an ASD, there needs to be a coordinated response for onward referral. The developmental services coordinator should arrange a multidisciplinary assessment of the child. In areas with large child populations, an Autism Spectrum Disorder coordinator may be appointed to assist the developmental services coordinator in this task (*Good Practice Point 1.2.11*).

- Contact details for the local developmental services coordinator and ASD coordinator should be widely disseminated to all potential referrers.
- The coordinator will also be responsible for collecting data and providing information to the Ministry of Health and District Health Boards for policy and planning purposes. Data to be collected include:
  - parental report of age of first developmental concerns
  - age at referral to the coordinator or to another professional service
  - duration of waiting time for multidisciplinary assessment
  - outcome of assessment
  - time until specified services and supports are in place for the child.

- Outcome data could include:
  - diagnosis of autism or Asperger syndrome by ICD-10<sup>20</sup> or DSM-IV<sup>21</sup> criteria, or ASD by DSM-5<sup>19</sup> criteria
  - autism spectrum disorder diagnosis, or other diagnosis
  - presence of co-morbid conditions
  - level of verbal and non-verbal developmental function.

**Note:** It is not intended that an ASD or developmental disorder register be established, rather that the efficiency of service provision and service gaps be identified by data collection.

#### 4. Multidisciplinary assessment

A multidisciplinary specialist assessment team involves a group of professionals working collaboratively to assess the child. This team usually includes at least two or three members drawn from the following professions: paediatricians, child and adolescent psychiatrists, clinical or educational psychologists, speech-language therapists and occupational therapists.

The preferred model of assessment process is a concurrent assessment by a collaborating team. If this is not feasible, the process could involve sequential assessments by individual professionals who then share their findings with one another. Each professional provides insights from his/her area of expertise which are then integrated and synthesised through an interactive group process. This approach will lead to more robust diagnosis, more accurate planning of future services and supports, and will reduce repetition and redundancy. Where a paediatrician or child and adolescent psychiatrist is not present at the multidisciplinary assessment, a separate medical assessment, including physical examination, is required by one of these professionals.

Specialist assessment teams are multidisciplinary, and may be multiagency (team members employed by different health and education providers such as Ministry of Education, Special Education, Child Development teams, Child Adolescent and Family Mental Health Service) or provided within one agency. Multiagency teams are preferred to prevent the child and family having to undergo repeated assessments and to ensure timely access to all the services needed.

Occasionally, the local multidisciplinary specialist assessment team will be unable to make a diagnosis. This may occur where the clinical features are atypical or complex. In this situation, local clinicians should be able to access assessment at a tertiary centre. It is envisaged that there should be a network of tertiary centres, with such assessments being available in main centres (*Good Practice Point 1.2.12*).

The NAPC Guideline has defined the following essential components of specialist team assessment. These have been adapted for New Zealand.

### **Essential components for a complete multiagency assessment**

Existing information from all settings should be gathered.

- A specific ASD developmental and family history should be taken. No evidence exists on which to recommend any particular framework, but this history should be taken by an experienced team member with recognised ASD professional learning and development. In some cases it may be useful to use a semi-structured interview such as the Autism Diagnostic Interview – Revised (ADI-R) or the Diagnostic Interview for Social and Communication Disorders (DISCO). If the person taking the developmental history is not medically trained, then

the medical history and examination should be completed separately.

- Focused observations should be taken across more than one setting as the familiarity of the setting often has significant impact on the skills and behaviours demonstrated by the child. These settings usually include home, early childhood centre or school. In some cases, observations at multiple settings are particularly useful for further assessment and clarifying the diagnosis. Direct observations need to be systematic and examine communication, social and play skills. This could include tools such as the Autism Diagnostic Observation Schedule – Generic (ADOS-G).
- Direct observation of the child's behaviour in an unstructured setting is essential. This is possible during the history taking as the child will often display behaviours that may be of concern to the parents and can help clarify information provided by the parent, for example how the child is responding to gesture. It also gives opportunity for the team to observe patterns of interactions within the family and with unfamiliar adults. The interview setting should include a selection of toys for children at a range of developmental levels – sensory, functional, symbolic and so on.
- The focus of the assessment of primary school-aged children should include their functioning in an educational setting and include observations of their behaviours in both classroom and playground settings. With older verbal children, assessment may also include a formal or informal child interview to provide further information on pragmatic skills and diagnostic features of communicative style.

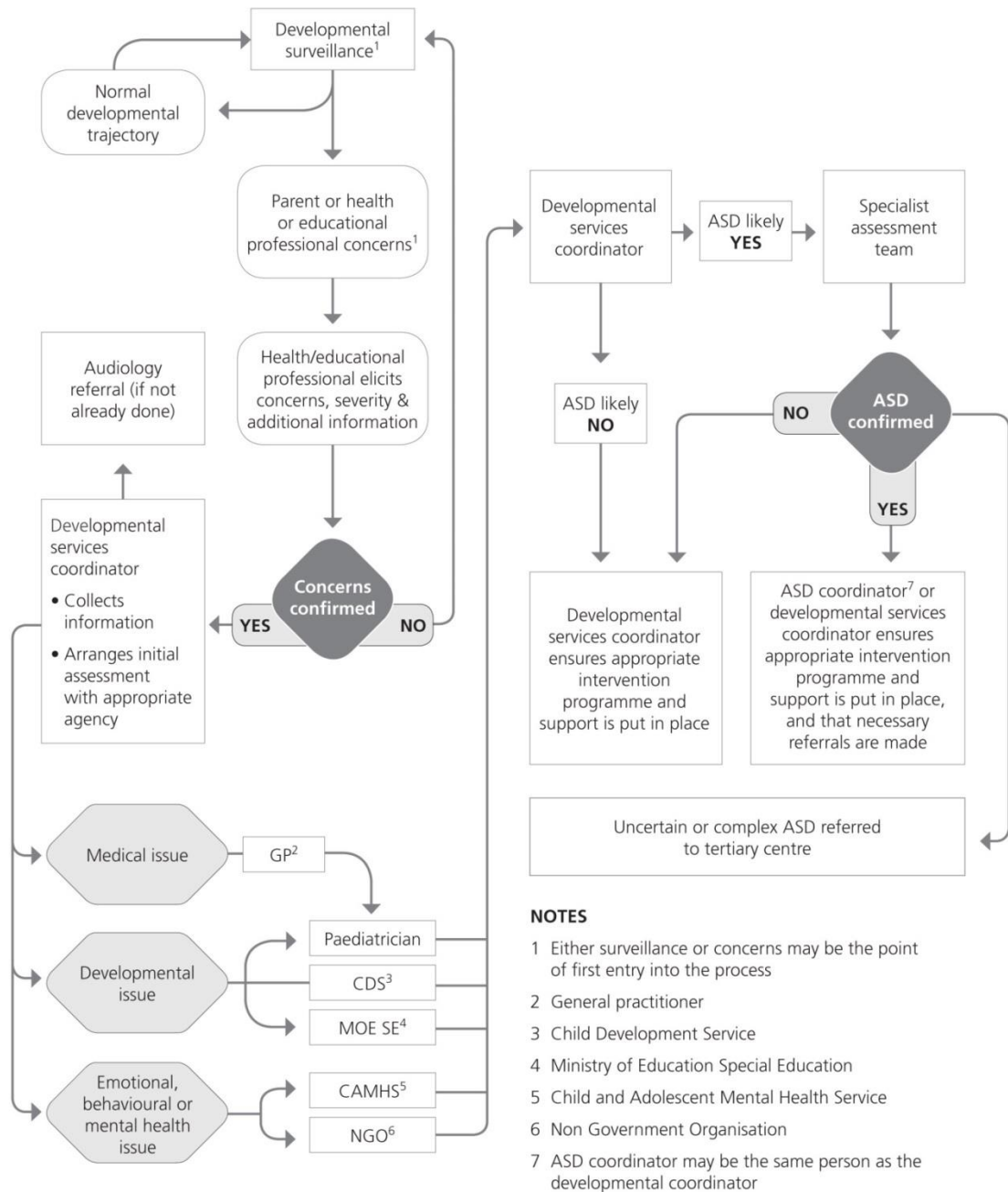
- If possible, a cognitive assessment should be performed in an appropriate setting by either a clinical or an educational psychologist with ASD-specific skills and experience. Skills and weaknesses found in cognitive assessment may not significantly contribute to clinical diagnosis but may assist in predictors of outcome and prognosis.
- A communication assessment should be made, and speech and language competencies assessed where needed by a speech-language therapist with ASD-specific skills and experience. Formal tests do not provide a comprehensive picture of a child's communication skills, especially for young children, and their results must be viewed qualitatively with other information. Observations of a child's understanding, pragmatic skills and symbolic understanding need to be made in informal settings. Where necessary, adaptations to play activities can be made to elicit specific skills.
- An assessment should be made of mental health and behaviour. Co-morbid mental health and behaviour problems are common.
- An assessment of the needs and strengths of all family members should be undertaken. If not already performed, a referral should be made to the appropriate Needs Assessment and Service Coordination (NASC) Agency.
- A full physical examination should be performed.
- Appropriate medical tests should be ordered. Choice of tests will depend on each child's clinical presentation, but chromosome karyotype and fragile X DNA analysis are the only current routine recommendations (Grade B). Clinical evidence of co-morbid medical conditions such as epilepsy should be sought but tests such as EEG should not be undertaken unless clinically appropriate. The evidence base for all investigations should be fully explained to parents.
- Other assessments may be required to investigate unusual sensory responses, motor planning and coordination difficulties, and self-care problems. These assessments should be carried out by a therapist with appropriate experience in ASD. On occasions, the therapist will wish to involve another health professional. Joint assessments are preferable.
- The findings should be discussed with the family/whānau and a plan developed including referrals for further assessment/intervention, review of the child and provision of a comprehensive report.

After the assessment is completed, the DSC (or ASD coordinator, where available) should ensure that the child (where appropriate) and family have received information about services and supports and that the relevant referrals have been made.

Current Ministry of Health elective guidelines require referrals to be seen within six months. All agencies should work together to ensure that waiting times are minimised, especially for children in the early childhood years, and that assessments are completed as quickly as possible within the available resources.



**Figure 1: Flowchart of identification and assessment process for children (aged < 16 years) who may have ASD**





## 1.2.b Young people and adults

### The diagnostic team and sources of diagnostic assessment

Interagency or multidisciplinary assessments or both are recommended for young people and adults suspected of having an ASD<sup>41 47–50</sup> (*Recommendation 1.2.2*). Although it is possible for a single clinician with experience evaluating ASD to make a diagnosis in very young children, assessment and diagnosis by a team of health care practitioners experienced in ASD is recommended for older individuals.<sup>41</sup> In New Zealand, recommendations and proposals have been made for the development of specialist ASD services which could undertake this role for people with ASD of all ages,<sup>51–53</sup> but they have not been implemented.

Currently, within New Zealand, there is no formal referral pathway for ASD assessment and diagnosis of adults. In some areas, referral pathways for young people are also unclear (*Recommendation 1.2.3*). Private health care practitioners are often approached to carry out diagnostic assessments. The health care practitioners most likely to be able to diagnose ASD in young people and adults include clinical psychologists, educational psychologists, child and adolescent psychiatrists and adult mental health psychiatrists (*Recommendation 1.2.2*). However, not all health care practitioners have expertise in ASD, and identifying ASD-competent health care practitioners able to diagnose older adolescents and adults is an ongoing issue. When seeking a practitioner or team to undertake a diagnostic assessment, the choice of health care practitioner should be based on their post-qualification education and areas of specialisation, and recommendations from within the ASD community (*Good Practice Point 6.26, Professional learning and development*).

A suggested pathway for the identification and assessment process for young people and adults who may have ASD is outlined in Figure 2 which can be found at the end of this section.

### Components of diagnostic assessment

Diagnostic assessment for young children has been outlined in section 1.2.a. A similar assessment should be undertaken for young people and adults.<sup>41 54</sup> Diagnosing people from these age groups presents a number of challenges, however, which include:

- recognising the wide range of expression of the symptoms of ASD which are influenced by the person's level of maturity, lifetime experiences and cognitive ability<sup>46</sup>
- the likelihood of more complex differential diagnosis because of the increasing possibility of alternative diagnoses and co-morbid conditions<sup>54</sup>
- competing diagnoses which may overshadow ASD
- difficulty obtaining accurate and detailed early developmental history as the age of the individual increases.<sup>27 46</sup>

Research and expert opinion support diagnostic assessment that includes the following components:

- detailed health, developmental and behavioural history (usually from parents and other informants)
- detailed assessment of patterns of skills, disabilities and behaviours
- comprehensive record and file review
- medical evaluation
- social and emotional abilities and interactions
- direct evaluation of the person through interview and observation in a range of environments

- formal assessment of intellectual functioning, in order to better understand the person's abilities and their prognosis, but not as a diagnostic tool in itself
- assessment of adaptive functioning (those skills needed for independent living), also in order to better understand the person's abilities (note that professional tests users should be aware of ASD norms for the Vineland adaptive behaviour scales<sup>55</sup> and other ASD relevant research)<sup>56–58</sup>
- assessment of other forms of cognitive functioning (*see below*)
- neurological assessment
- mental health assessments
- communication and audiological assessment
- sensory, motor and perceptual assessments
- vision assessment
- occupational and physical therapy evaluation
- evaluation of social competence and functioning
- evaluation of interests and activities
- assessment of family resources and needs<sup>27 41 42 49 50 59 60–62</sup>  
(*Recommendation 1.2.4*).

The use of standardised interviews and assessment formats for autism, Asperger syndrome and ASD is supported,<sup>63</sup> and assessment processes are regularly reviewed and refined as understanding of ASD develops further<sup>64–67</sup> (*Recommendation 1.2.5*). Currently, commonly recommended tools include:

- Autism Diagnostic Interview – Revised (ADI-R), a standardised, semi-structured clinical review for carers of children and adults suspected of having autism or other pervasive developmental disorders<sup>66 68–70</sup>
- Autism Diagnostic Observation Schedule – Generic (ADOS-G), a semi-structured, standardised assessment of social interaction, communication, play and imaginative use of materials, for use with children and adults suspected of having autism or other pervasive developmental disorders<sup>66 71 72</sup>
- Asperger Syndrome Diagnostic Interview, a clinician-administered tool for use with children and adults suspected of having Asperger syndrome or High Functioning Autism<sup>73</sup>
- Autism Spectrum Disorder Screening Adults Questionnaire (ASDAQ), a screening test for ASD in the adult population<sup>74</sup>
- Autism Spectrum Quotient (AQ), a self-administered screening test for people suspected of High Functioning Autism/Asperger syndrome<sup>75</sup>
- Australian Scale for Asperger's syndrome (ASAS), a checklist for parents of primary school children suspected of having Asperger syndrome<sup>76</sup>
- Childhood Asperger Syndrome Test (CAST), a parent-completed screening test for children aged 5–11 years<sup>77</sup>
- Developmental, Diagnostic and Dimensional Interview (3di), a computerised assessment for autism spectrum disorders<sup>78</sup>
- Diagnostic Interview for Social and Communicative Disorders (DISCO), a clinician-administered schedule of assessment for use with people of all ages<sup>79 80</sup>

- Gilliam Asperger's Disorder Scale (GADS), a scale for use by parents and professionals, assessing Asperger syndrome in people aged 3–22 years<sup>81</sup>
- Krug Asperger's Disorder Index (KADI), a scale for use by professionals, assessing Asperger syndrome in people aged 6–22 years.<sup>82</sup>

Many of the tests above are subject to ongoing review and limitations are described in the literature and Appendix 5. Many of the tools require specialist education which is not currently available in New Zealand (*Recommendation 1.2.6, Recommendation 6.2, Professional learning and development*).

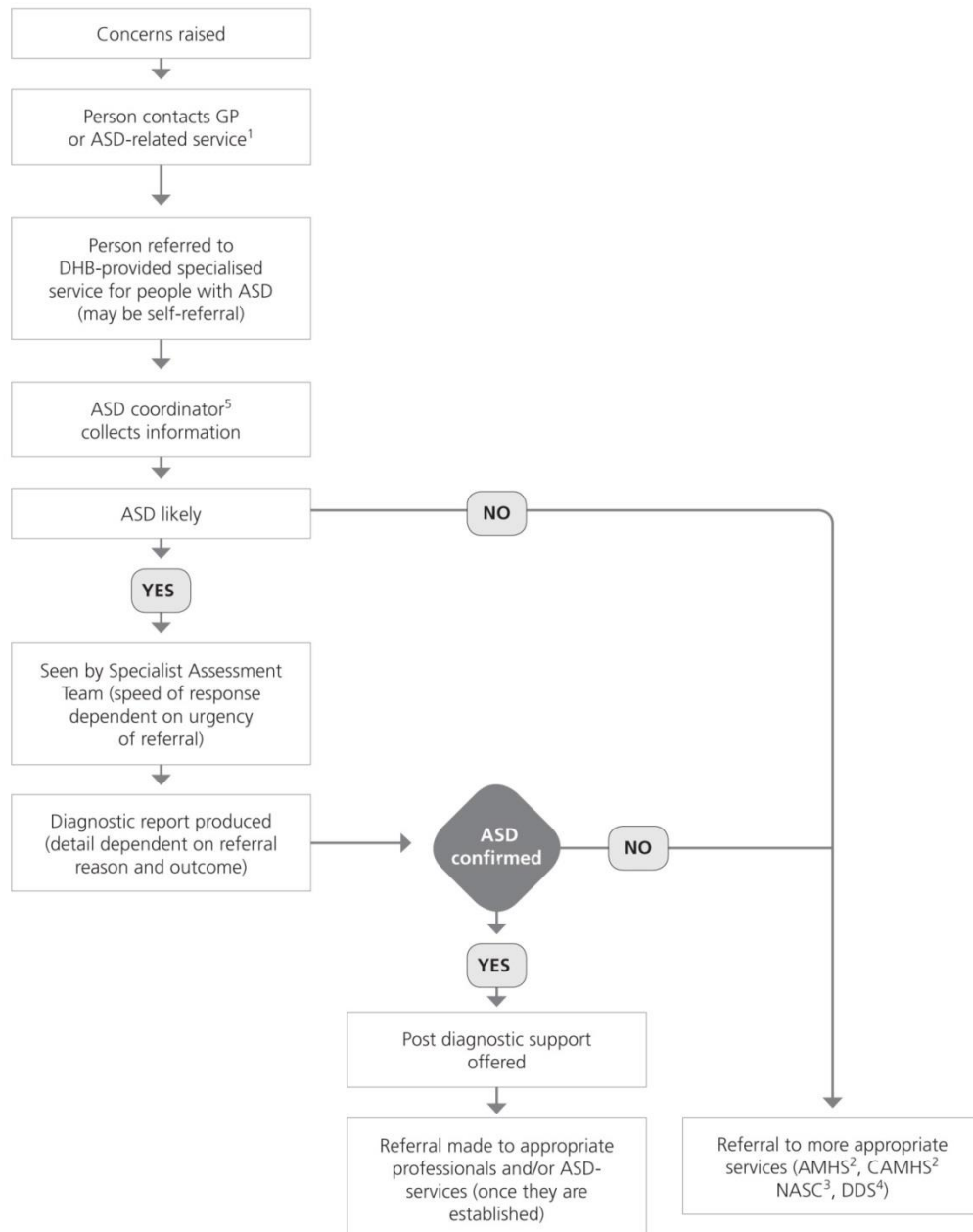
Theory and research on the nature of ASD is complex, controversial and ongoing.<sup>83 84</sup> The three main theoretical approaches are:

- disturbance in theory of mind or 'mindblindness': impaired ability to reflect on the contents of one's own and others' minds<sup>85</sup>
- weak central coherence theory: the difficulty that people with ASD have in cognitively 'seeing the big picture', and their focus on the smallest possible parts
- executive dysfunction theory: impaired ability to perform tasks involving 'executive function' (eg, planning, working memory, impulse control, inhibition, shifting set, initiating and monitoring action).<sup>86</sup>

Assessment related to the above psychological theories of ASD and specific cognitive functions may lead to a fuller understanding of an individual's strengths and needs and, in turn, inform intervention and support<sup>87</sup> (*Recommendation 1.2.7*). Summary of this work is beyond the scope of the New Zealand ASD Guideline, but interested professionals may find it useful to follow up on some associated references.<sup>82 83 87–96</sup>

No studies were identified which addressed the validity of applying any of the measures listed above to the New Zealand population. As no New Zealand norms have been published, information is lacking on the applicability of these tools to New Zealanders of any ethnic background and on the sensitivity or specificity of the tools (*Recommendation 1.2.13, Recommendation 6.3, Professional learning and development*).

**Figure 2: Flowchart of identification and assessment process for young people and adults who may have ASD**



**NOTES**

- 1 ASD Disability and Information Service (ASD DIAS), Autism New Zealand, ASD Information Network (ASDIN)
- 2 Adult Mental Health Service and Child Adolescent Mental Health Services
- 3 Needs Assessment & Coordination Service
- 4 Dual Diagnosis Service
- 5 The title of ASD coordinator for adults and adolescents could be subject to change following implementation

### 1.3 Differential diagnosis of autism and consideration of other possible conditions

#### Summary of recommendations

Recommendations:	Grade
1.3.1 Differential diagnosis must be covered during diagnostic assessment.	C
1.3.2 Differential diagnosis must be thorough and cover all conditions commonly confused with ASD and those known to coexist with ASD.	C
1.3.3 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

Good Practice Points:	
1.3.4 Health care professionals must consult with specialists in areas of diagnostic overlap when issues are not clear.	✓

#### 1.3.a Early childhood

There is no absolute test for ASD. While this is also true for many other situations, it is essential for clinicians providing assessment and diagnostic services for children with possible ASD to fully consider other possible diagnoses (the differential diagnosis)<sup>42 88</sup> (*Recommendation 1.3.1*).

When a child is being assessed for autism, other diagnoses need to be considered, such as:

- hearing impairment
- auditory processing disorder
- environmental deprivation
- attachment disorder
- specific language disorder
- semantic pragmatic language disorder
- dyspraxia
- intellectual disability
- selective mutism
- mental health disorders, such as attention deficit hyperactivity disorder and opposition defiant disorder
- conduct disorder in the older child
- abuse, trauma, neglect.

These disorders may also occur in association with ASD. Other conditions occur more commonly in association with ASD than in the general population. When two different conditions or disorders occur together in the same individual they are called co-morbidities.<sup>88 89</sup>

They include:

- attention deficit hyperactivity disorder
- anxiety disorders (including obsessive-compulsive disorder)
- Tourette syndrome
- depression
- developmental dyspraxia/developmental coordination disorder
- epilepsy
- nutritional deficiencies secondary to restricted diet
- specific learning disability or intellectual disability.

If a co-morbidity is suspected, then an appropriate evaluation should be carried out and a treatment plan put in place (*Recommendation 1.3.2*).

An increasing number of specific medical conditions have been described as being associated with autistic symptomatology. These include:

- degenerative neurological or metabolic condition
- Down syndrome
- fetal alcohol spectrum disorder
- fragile X
- Rett syndrome
- tuberose sclerosis.

Every child with a developmental problem for which no cause is obvious should have a paediatric evaluation and an appropriate focused investigation, depending on the findings from that evaluation

(*Recommendation 1.3.3*). All children with a language delay or difficulty should have an audiology hearing assessment as part of their evaluation.

Any child in whom there is a history of possible developmental regression should have the possibility of neurodegenerative disease or metabolic disorder considered and appropriately investigated. This should involve consultation with a paediatric neurologist or metabolic specialist, as appropriate.

In children where there is doubt about diagnosis and who have a history of abuse or disrupted early attachment, an opinion from a child psychiatrist or psychologist is necessary to consider possibilities such as:

- attachment disorders
- other psychiatric disorders, including schizophrenia and schizoid personality disorder in older children, adolescents and adults.

Management of epilepsy will not be addressed in this guideline. Children with uncomplicated epilepsy should be managed by a paediatrician. Children with complicated or refractory epilepsy should have an evaluation by a paediatric neurologist.

Pharmacotherapy in ASD and for other co-morbidities in association with ASD is discussed in section 4.4.

### 1.3.b Young people and adults

Careful differential diagnosis is extremely important for young people and adults (*Recommendation 1.3.1*). ASD can be misdiagnosed, for any number of psychiatric conditions can co-exist with or be superimposed on ASD.<sup>27 41 46 54</sup> Common differential diagnoses and/or coexisting conditions include schizophrenia, intellectual disability, catatonia, depression, anxiety disorders, obsessive-compulsive disorders, attention disorders, language disorders, disorders of impulse control, and substance abuse.<sup>41 42 59 90</sup>

Competent differential diagnosis in young people and adults relies on:

- the process being thorough
- the health care professionals involved having considerable experience in and knowledge of ASD, including an understanding of the different forms of expression of ASD symptomatology across developmental stages and the symptomatology of common coexisting and alternative conditions
- health care professionals consulting with specialists in areas of diagnostic overlap when issues are not clear (*Good Practice Point 1.3.4*)
- undertaking careful examination of the factors that prompted the referral
- collecting detailed history to discern whether potential symptoms of ASD present at the time of assessment were present (albeit possibly in different forms) at earlier stages of development
- careful delineation of symptomatology consistent with ASD, from

characteristics of coexisting or alternative diagnoses<sup>41</sup> (*Recommendation 1.3.2*).

A common diagnostic dilemma is whether to differentiate autism or high functioning autism from Asperger syndrome. Autistic disorder and Asperger disorder are separate diagnoses within the classification system most commonly utilised in New Zealand, the Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)<sup>90</sup> (see *Appendix 4*). Yet recent reviews on the conditions in children, young people and adults have found considerable overlap in symptoms and few qualitative differences,<sup>23 91 92 102–105</sup> and reviews of tests designed to discriminate between the conditions found that most could not differentiate reliably.<sup>64 65</sup> Consequently, some eminent researchers suggest that using the terms ASD or High Functioning Autism/Asperger syndrome is more appropriate, and/or use such terms in their own publications.<sup>93 94–97</sup> Given the current state of knowledge, a diagnosis of ASD is likely to be sufficient. The focus needs to be not so much on the specificity of the diagnosis but on an appropriate assessment and management plan.

**Note:** this approach is consistent with the latest edition of the Diagnostic and Statistical Manual for Mental Disorders, the DSM-5<sup>18</sup>, as discussed in the Living Guideline Group's Supplementary Paper on the implications of the DSM-5 for the guideline (see *Appendix 10.5 for a summary*).

## 1.4 Formulation, disclosure of diagnosis and post-diagnosis support

### Summary of recommendations

Recommendations:	Grade
1.4.1 Formulation is the necessary next step from assessment.	C
1.4.2 Clarity of diagnosis should be the goal of assessment and formulation.	C
1.4.3 In situations when diagnostic clarity is not possible, an action plan should be developed to attend to areas of complexity and confusion.	C
1.4.4 All diagnostic assessments should include a detailed written report covering the person's strengths and weaknesses, developmental course, ASD symptoms, recommendations for intervention and information on support networks.	C
1.4.5 Disclosure of diagnosis of older teens and adults and decisions about the involvement of family and whānau or support people should take into consideration the wishes of the person concerned, privacy issues and their support needs.	C
1.4.6 Information on ASD and support services should be available at all diagnostic disclosure interviews and through health and disability services.	B
1.4.7 Sources of post-diagnosis support should be identified for the person with ASD.	C

Good Practice Points:	
1.4.8 Disclosure of diagnosis of young teens should be family-centred and involve the family and whānau.	✓
1.4.9 The need for formal support pathways of post-diagnostic support for newly diagnosed people with ASD should be investigated further.	✓



Formulation is the process of integrating the assessment information systematically (*Recommendation 1.4.1*). This enables the diagnostic team to attend to differential diagnosis sufficiently, finalise their opinion and develop recommendations.<sup>41</sup> Ideally, through the process of formulation, the team will develop a single, coherent view of the child or person assessed (*Recommendation 1.4.2*). In cases where a definitive diagnosis is not possible, an action plan should be developed to address issues of complexity and confusion<sup>41</sup> (*Recommendation 1.4.3*). The formulation should become a written report detailing the person's strengths and weaknesses, developmental course, ASD symptoms and recommendations for intervention. It should also provide information on support networks<sup>41 47 54</sup> (*Recommendation 1.4.4*).

Whilst family-centred disclosure of diagnosis is recommended for children with ASD, careful clinical judgement and attention to issues of privacy is required when disclosing diagnosis of young people and adults (*Recommendation 1.4.5*). Younger teens and more dependent adults may prefer/require family and whānau involvement in disclosure (*Good Practice Point 1.4.8*). Older teens and more independent adults may prefer individual sessions, or to be accompanied by a support person of their choice.

Research on the satisfaction that parents of children diagnosed with ASD felt with the disclosure process suggested that higher satisfaction was associated with the quality of information given to them (including written reports), acceptance of their early suspicions about their child's development by professionals and being given a definite, rather than a tentative, diagnosis<sup>98</sup> (*Recommendation 1.4.6*). The study authors went on to advise professionals to be respectful, identify supports and be informed. Published advice to professionals disclosing diagnoses to young people and adults includes giving the person

concerned ample time to ask questions, to understand what is being said and to voice concerns.<sup>47 99</sup> Of interest to some may be the model used by a United States-based medical doctor to explain the diagnosis to parents of children with ASD (this may be able to be adapted for use with young people, adults and their families and whānau).<sup>100</sup> He recommended discussing the child's needs and likely prognosis while outlining four basic premises: that atypical development occurs along a continuum from mild to severe; that phenotypic expression of ASD varies with age; that ASD of any degree of severity can occur in combination with any degree of general intelligence; and that long-term prognosis represents the joint impact of ASD and the child's general level of intelligence.

People diagnosed with ASD and their families and whānau may raise issues which indicate a need for post-diagnostic support from an ASD specialist or specially trained psychologist or psychiatrist<sup>47</sup> (*Recommendation 1.4.7*). Common themes include doubt about the diagnosis, depression and despair, anger and fear.<sup>99</sup> However, some people find the diagnosis a relief, making sense of what have sometimes been years of difficulty.<sup>33</sup> Nevertheless, these people may also have significant issues.

Good post-diagnosis support helps the person to:

- understand ASD and how it affects his/her life
- access good-quality ASD information
- discover his or her financial entitlements (if any)
- identify services for specific ASD support
- network with other people with ASD
- source further counselling from appropriately skilled practitioners (*Good Practice Point 1.4.9*).



## Part 2

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Support for individuals, families and carers

“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...”

## Part 2 Support for individuals, families and carers

ASD has been described as a ‘hidden’ disability that affects every aspect of a person’s day-to-day life, including social inclusion. Some people with ASD will have significant support needs with everyday tasks while others will need low-level ongoing support to sustain education and employment or access to the community.<sup>101</sup> Studies have mostly focused on outcomes that are associated with the person with ASD. However, parents and whānau, partners, siblings and carers are key people in the lives of the person with ASD, and they have additional needs for support that must be considered to ensure that they, too, enjoy social inclusion to the degree other community members take for granted. People with ASD also need support to improve their wellbeing.

This section of the ASD Guideline identifies the key support and service needs for people who live with, love and care for individuals with ASD. It also covers the health care needs of people with ASD that need to be addressed to enhance their wellbeing.

## 2.1 Relationships

### Summary of recommendations

Recommendations:		Grade
2.1.1	The values, knowledge, preferences and cultural perspectives of the family/whānau should be respected and evident in services and resources.	C
2.1.2	The stress experienced by the families and whānau of children with ASD should be acknowledged.	C
2.1.3	The value of parent-led support networks should be recognised in helping parents to deal with the issues that they are facing following diagnosis and in supporting access to information.	B
2.1.4	Teachers and other professionals should collect and appreciate the unique information about the child, which is held by the parent. This information should be incorporated into the planning of the child's education programme.	B
2.1.5	The parents' role in interventions should be respectfully negotiated.	B
2.1.6	Planning and evaluation of interventions should always take into account both family/whānau and child variables and outcomes.	B
2.1.7	ASD-related counselling and/or advocacy services and education should be available to all family members and carers.	C
2.1.8	Further research is needed to identify the needs of children parented by people with ASD and the needs of parents with ASD.	C

Good Practice Point:	
2.1.9	The perspective of grandparents should be researched to investigate the therapeutic and cost-effectiveness of involving grandparents as part of the assessment process and to identify the importance of their role in their ongoing support of family/whānau.



### 2.1.a Parents and full-time carers

#### Emotional and financial stresses

There is significant agreement that having a child with ASD places additional stresses on parents (especially mothers), families and whānau. There is speculation that the lack of interpersonal responsiveness might be a major reason for this, over and above the difficulty of having a child with a significant disability.<sup>102</sup> Factors associated with parent and family psychological distress include low levels of support from within the family and bringing up a child with challenging behaviour.<sup>103</sup>

Parental perception can have an impact on how well parents cope. Mothers who feel they are to blame for their child's disability or those who find the child's needs to be a catastrophe for the family tend to have more difficulty adapting. In contrast, perceived social support (such as supportive partners) and psychological hardiness (an understanding and acceptance of the diagnosis) tend to protect mothers from the effects of stress.<sup>104</sup>

Most of the literature describes parents' experiences of helping a person with ASD to develop skills and enjoy activities as hard work and time consuming, and the additional demands of caring for a family member with ASD often continue into adulthood. Combining this with bringing up other children poses challenges in meeting the needs of the whole family.<sup>31 47</sup> These challenges are more complex if families have more than one family member on the spectrum.<sup>105</sup> The behaviour of the person with ASD will impact on other members of the family and balancing the needs of other children will require extra consideration. Despite these demands, families and whānau are often extremely resilient and develop excellent coping strategies, including strengths-focused problem solving.<sup>104 106</sup>

Longitudinal research on the experiences of parents and families as they adapt to the changing needs of a family member with ASD is scarce. Research tends to concentrate on mothers and has a focus on the negative aspects of ASD, with limited research on cultural influences. Little is known about the long-term experiences of families who have children with Asperger syndrome.<sup>107–109</sup>

Research shows the economic and social impact of caring for family members with disabilities.<sup>31 110–112</sup> Combined with the cost of therapies and medication, interventions and support services and lost earnings, ASD is acknowledged to be a costly disorder. Flexible community-based and employer supports are crucial to support parents of children with disabilities to enable them to work and care for their children.<sup>110</sup>

#### Support and respite to minimise stress

Timely and more effective early support for the management of children with ASD may reduce the need for full-time 24-hour out-of-home placements of some young children with ASD.<sup>11</sup> Providing support to families who care for a child with ASD may result in a significant cost-benefit to government, saving expensive crisis management and providing quality of life to people with ASD and their families<sup>113</sup> (*Recommendations 2.1.1, 2.1.2*). Evidence suggests that the provision of respite care and a key worker case management model is likely to lead to the most positive outcomes for parents.<sup>111 113 115</sup>

The value of parent-led support networks has also been identified.<sup>114</sup> Parents want help to deal with the issues they are facing following diagnosis. Parent-to-parent support enables new parents to feel less isolated and encourages access to information<sup>115</sup> (*Recommendation 2.1.3*).

The strongest evidence for reducing stress in mothers identified the success of more structured interventions, such as cognitive behavioural interventions. There is a lack of evidence for alternative models to cognitive behaviour therapy, including culturally appropriate elements and how and when to involve other family members.<sup>114</sup>

### Parent–professional collaboration

The evidence is clear that regardless of the intervention, implementing it across home, early childhood education services, school and community settings is important to the outcomes. However, the high level of participation that is associated with effective outcomes does put considerable demands on parents.<sup>104</sup>

Parents have to take on multiple roles when their child has ASD. Engagement of parents is crucial, but the degree to which they are involved will differ, depending on family wishes and circumstances. Some parents just want to be ‘Mum’ or ‘Dad’ and not the child’s teacher, and this should be respected. When planning interventions, parents and professionals need to agree on the roles and responsibilities each wishes to take. These roles may change at times to reflect the specific needs of the child and his or her family.<sup>11 116 117</sup>

Eco-cultural theories hold that family values are embedded in daily routines and families and whānau maintain these routines in order to adapt to their environment. Research suggests that interventions need to accommodate these routines or they will not be sustainable.<sup>106</sup> It is important that the skills which are targeted in individual plans are functional and able to be practised in both home and educational settings.<sup>104</sup>

Collaboration is associated with effective outcomes. A collaborative intervention considers that the child’s and family/whānau’s characteristics (values, culture and resources) are important in designing interventions and routines. A review of parent roles in intervention reported greater improvements for children following a collaborative-consultation model than with a teacher-only model<sup>106</sup> (*Recommendation 2.1.4*).

Family participation is effectively supported by education providers through ongoing consultation and individualised problem solving, as well as through opportunities to learn techniques for teaching their children. While parents cannot be expected to provide the majority of educational programming for their child, their concerns and perspectives should actively shape educational planning<sup>104</sup> (*Recommendation 2.1.5*).

Support for New Zealand families during the diagnostic process is outlined in Part 1 of this guideline. Key actions recommended, specifically for families following assessment and diagnosis,<sup>11</sup> include:

- easy access for families to information and support relating to their needs
- immediate appointment of a key worker who has ASD expertise for coordination of interventions and supports for the child and family, with an outline of agreed time scales and dates (this person is not the same as the ASD coordinator who coordinates referral)
- care plan developed with and for the family which includes care management for complex situations and ongoing needs
- consideration of the needs of siblings as part of the care plan.

There is increasing awareness about the practical and emotional needs of family members and the central role they can play in the family's adaptation to ASD. Virtually all parents of children with special education needs require support, partnership and substantial new skills and knowledge learned in the context of the needs of their particular child. Families' and whānau's knowledge, beliefs, aspirations, values, culture and preference for services must be recognised and used for planning and provision of supports and services<sup>11 118</sup> (*Recommendations 2.1.5, 2.1.6*).

Observational research acknowledges the important role that parents have in any intervention process, but specific guidance is lacking on the potential advantages and disadvantages of different parent-mediated approaches to providing early intervention. A Cochrane systematic review, including two small randomised controlled trials (RCTs), was unable to offer guidance for practice from its findings.<sup>119</sup>

All staff working with a child should liaise closely to develop an individual plan and a family care plan, which include clear goals and strategies and which are updated regularly. Family care plans should be written in a clear format and, where necessary, intensive ASD service coordination should be provided to assist in accessing services provided by a joint funding provision.<sup>11</sup>

## Advocacy

It is important to make information available to parents so they are able to take an active role in advocacy for their children's education if they wish.<sup>104</sup>

Specialists and teachers can support parents to master an understanding of the vocabulary and systems of education, the characteristics of ASD, how those are related to a child's educational needs and gain an appreciation of how intervention techniques work. Without this knowledge, it is unfair and unreasonable to expect a parent to be an effective collaborator or good advocate for his or her child.<sup>104</sup>

Education in advocacy skills should be available for parents and individuals with ASD (*see also section 4.2 Problem minimisation and avoidance*). Conflict resolution skills may be useful for both parents and school staff to ensure that both groups are well informed and to ease tensions that may arise through their interactions. There is always the potential for conflict and both parties need to be supported in learning how to disagree and resolve differences within a constructive atmosphere. Parents who do not feel confident to advocate themselves should be offered access to quality advocacy services<sup>104</sup> (*Recommendation 2.1.7*).



### Rural issues

Rural families and whānau experience significant challenges and disadvantages in accessing resources and services (eg, transportation, lack of local support, isolation, financial resources, lack of employment opportunities) compared with urban dwellers. Distance education programmes may be one way to make information accessible. Literature about provision of services to families and whānau of children in rural areas is scarce. There have been promising results for distance education programmes for parents of children with challenging behaviours (one based on written materials with weekly telephone contact and one delivered through television).<sup>106</sup>

### Cultural issues

Cultural differences need to be recognised and appropriately acknowledged. If teachers and other professionals do not understand what the child's ASD means to a family/whānau, it will be difficult for them to develop the kind of collaborative relationship which is essential for the education of children with ASD. Cultural sensitivity will mean providing services in a language in which parents are fluent as well as an understanding that views of disability may differ for some ethnic or racial groups.<sup>11 117</sup>

In New Zealand, it has been suggested that people working with Māori learners with special education needs should not make assumptions or unilateral decisions about what is culturally appropriate for a learner and what degree of cultural input is required. These decisions must be made in consultation and collaboration with the learners, parents and whānau concerned.<sup>120</sup>

A recent qualitative study which examined Māori perspectives of ASD identified that, although parents' experiences of diagnosis were variable, many parents were well informed.<sup>116</sup> Most had encountered both helpful services and services with barriers. The report identified a number of areas of concern that highlighted the need for education in ASD. Parents had a wide range of views with respect to cultural input into service provision and saw Māori-medium education and services as having advantages and disadvantages (inclusive supportive staff versus a lack of knowledge about ASD).

A study that looked at access to 'EarlyBird', an education programme for parents of children before they start school, identified other cultural issues as raising barriers to parent education in New Zealand. As well as language barriers, the study identified late diagnosis, difficulties in attending programmes due to work and family commitments and a need for a more community focused approach.<sup>121</sup> Further information on Māori and Pacific peoples' perspectives of ASD is included in Parts 7 and 8.

### 2.1.b Siblings

There are special demands placed on the siblings who live with family members with ASD. Learning how to manage these demands can help brothers and sisters to cope with their experiences, through access both to developmentally appropriate information and to specific strategies to help meet the distinctive challenges of living with a sibling with a disability.<sup>122 123</sup>

Studies on the effects of children with disabilities on the wellbeing of their non-disabled siblings and/or the quality of the sibling relationship provide contradictory results, partially explained by methodological problems (such as choice of comparison groups). Research does, however, identify that while siblings of children with ASD experience their own stress and often bear more responsibilities than children with typically developing siblings, a disabled sibling does not necessarily lead to a problematic sibling relationship. Positive sibling relationships are enhanced by the siblings having knowledge of the ASD disorder and through support programmes for siblings that are provided by support groups for children with similar disorders. Longitudinal studies have been recommended to determine whether relationships remain positive with age and/or increasing responsibilities on the part of the non-disabled sibling.<sup>124–127</sup>

There is increasing awareness of the needs of other family members and the role they play through practical and emotional support. Thus, the current and future needs of family members should be considered when interventions and supports are identified for their disabled sibling and these needs should become part of a care plan.<sup>11</sup>

It is important that the personal needs of siblings are not overlooked. They should have an opportunity to learn about ASD and to have access to sibling support groups<sup>124 127</sup> or one-to-one counselling or both, where appropriate. Research suggests that peer instruction from siblings can contribute to behavioural and social changes in their brothers or sisters.<sup>102</sup> Siblings who attend the same school as their brother or sister with ASD also need support in situations where they might be asked for help by teaching staff or where they are teased about or embarrassed by their sibling's behaviour.

It is important to remember that the needs of siblings will change over time.<sup>11</sup> There is a lack of evidence on the effects of a diagnosis of ASD within the family on non-disabled siblings. Siblings need information and support post-diagnosis and ongoing support throughout their development. Further research is needed to identify the variety of formal and informal social supports that best sustain non-disabled siblings and their relationships with their sibling with ASD,<sup>125</sup> and to determine what types of information might be effective for siblings of different ages.<sup>128</sup>

Information about ASD for siblings can be sourced through support groups and libraries, disability related websites and links specifically designed for siblings. Computer-mediated self-help groups are another possibility, although there is, so far, little research in this area. One study, of the online conversations of young individuals who participated in Sibkids, an online support group, identified three main categories of social support that were provided: emotional support, informational support and social companionship.<sup>129</sup> This suggests that there is a potential for children and adolescents to receive multidimensional social support from online chat groups.

Siblings are at greater risk of showing symptoms of ASD than the general population. Younger siblings, particularly, require close monitoring to ensure that if they have indicators, intervention can begin very early.<sup>104</sup>

### 2.1.c Grandparents

Even when generally supportive, extended family and whānau such as grandparents can struggle to provide practical and emotional support because of difficulties coming to terms with the diagnosis and the challenging behaviours of children with ASD. Community awareness and understanding of ASD are important to overcoming these barriers.<sup>116</sup>

Three key themes were identified from a qualitative study on the experiences of six grandparents of children diagnosed with ASD: the parental bond towards the grandchild and adult child, striving for answers (the search for meaning) and the role of grandparents in holding the family together.<sup>130</sup> Their role in helping to inform clinical assessment work is unclear and there is a lack of evidence on the therapeutic value and cost-effectiveness of involving grandparents as part of the assessment process (*Good Practice Point 2.1.9*).

New Zealand child-protection law requires that children be placed within their extended family/whānau, if possible, when in need of care and in many cases it is grandparents who take on the caring role. Many others take care of their grandchildren in response to a family crisis without any formal or statutory intervention.<sup>131</sup> Anecdotally, it is known that some grandparents who may have looked forward to retirement after parenting their own ASD child(ren), find themselves caring for their grandchildren who have been diagnosed with an ASD. Whatever the circumstances, information, support and services are essential to help grandparents to cope. A New Zealand handbook for grandparents and other kin carers exists which is a comprehensive resource – including further references and contacts for agencies – for grandparents who find themselves in this situation.<sup>131</sup>

### 2.1.d Formal carers

Formal carers are those people who are paid to care for people who are placed outside their family home. Education, opportunities to discuss professional practices and having breaks are seen as necessary supports for carers. There is a lack of ASD-specific evidence in this area and further research into their support needs is recommended.

### 2.1.e Spouses and life partners

People with ASD do have intimate relationships, inclusive of marriage, life partnerships and homosexual relationships, although it should be noted that not all adults with ASD will want or attain a long-term relationship. Although this is an area that remains under-researched, personal accounts by both partners and individuals with ASD can be found in the literature<sup>33 132</sup> including perspectives provided by counsellors.<sup>133</sup>

Challenges to these relationships include difficulties that are directly related to ASD, particularly in relation to communication, socialising and imaginative thought. How a partner approaches and copes with the many difficulties that having ASD can present makes a difference to the coping mechanisms of both partners.<sup>133</sup> Appropriate support services are needed for adults with ASD and their partners.

A review of literature, anecdotal information and websites identifies a number of supports that spouses and partners can access to support them in their relationships, including how to:

- learn about ASD and how it affects their loved one
- establish routines that work for both partners – this can include negotiating formal agreements about things that cause problems

- access genetic counselling, if planning to have children
- access relationship assistance if needed – the counsellor must know about ASD
- handle separation and divorce, which present special issues.

In order to support spouses and life partners, health and education professional development curricula need to:

- ensure that any professional learning and development for ASD offered to health and education professionals through their institutions includes knowledge and awareness of the needs of this specific group of people
- ensure that social service staff members receive adequate education in child-welfare issues relating to parents who have ASD<sup>47</sup> (*Recommendation 6.4, Professional learning and development*).

#### **2.1.f People raised by parents with ASD**

There is limited information on what it means to be parented by someone who has ASD. A small number of websites and publications provide personal insights from adults.<sup>134–136</sup> Very little research information was identified on the experiences of young children parented by people with ASD (*Recommendation 2.1.8*). A number of important child-welfare issues need to be addressed when the parenting threshold for an ASD parent has been exceeded, including the needs of children in custody arrangements or following the death of a parent.

A number of issues are raised in calling for further research to better support people with ASD in their role as parents,<sup>135</sup> including:

- research on the needs of parents with ASD
- research to identify the needs of children parented by people with ASD
- parent education and workshops which offer ASD-appropriate supports and resources
- specific training for counsellors to work with children who are parented by people with ASD (*Recommendation 6.5, Professional learning and development*).

## 2.2 Parent information and education

### Summary of recommendations

Recommendations:	Grade
<p>2.2.1 Family members and whānau need to know how to find and access information and support.</p> <p>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.</p>	C
<p>2.2.2 All education services should be family/whānau-centred.</p>	B
<p>2.2.3 A key service to support families and whānau is the provision of 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.</p>	C

The critical role parents play in supporting their children's learning is highlighted by a meta-analysis of health and aging undertaken for the Australian Government to identify the most effective models of practice in early intervention for children with ASD. Emotional support, advice and education are required by parents to enable them to work effectively with their children. Parents also need access to up-to-date information about treatment options and support services. The research acknowledged that information, support and education should be provided for the entire family unit. The Australian report also commented on the needs of ethnic minorities, socioeconomically disadvantaged families and people living in rural areas who require special consideration.<sup>137</sup>

A key service to support families is the provision of information about ASD. Increased media attention and the widespread availability of the Internet have increased parents' knowledge, but these sources can convey perspectives that are not balanced or well-supported scientifically. Parents need access to balanced information about ASD and the range of appropriate services and technologies<sup>104</sup> (*Recommendation 2.2.1*). The information needs to be accessible to everyone and include culturally appropriate material in an easy-to-read format that is developmentally appropriate. Support groups and government should work in close association to ensure all information is kept up to date.<sup>47</sup> Readiness for education in families with a newly diagnosed child needs to be carefully handled and evaluated.

Information that can assist parents might include:

- scientifically based, specialised knowledge and skills about ASD and its treatment
- guidance on mastering specific teaching strategies that enable them to help their child acquire new skills and behaviours
- information on understanding how ASD influences their child's learning and behaviour
- guidance on understanding their rights and responsibilities in the education system in order to effectively advocate for their child
- help in coping with the emotional stress that can follow from having a child with a significant developmental disorder.<sup>106</sup>

Sound information from appropriately qualified professionals can also assist parents to make good decisions and maintain a sense of control. Parents require timely information about assessments, education plans and the available resources for their children to be conveyed in a meaningful way that gives them time to prepare to fulfil their roles and responsibilities.<sup>104</sup>

In a qualitative study of 19 Māori families and whānau in New Zealand, parents reported finding a range of information to be helpful: verbal explanations of ASD at point of diagnosis; a good talk with someone who knew about ASD; how they could assist their child; future implications; and what services, equipment and entitlements existed. Parents wanted to know not only how these could be obtained, but who could assist them in the process. Useful sources of information were identified: taped and written information (ranging from pamphlets and books), videos, conference attendance and web-based information.<sup>116</sup>

In some situations, Pacific people may feel that asking for help, which can extend to seeking out services, is rude. In their communities, help is usually offered rather than requested.<sup>138</sup> Traditionally, family issues and problems are kept very private and often hidden and families can find it extremely difficult to actively seek help and ask for available services and supports, especially where there are gaps in services. Information therefore needs to be offered to people rather than expecting them to initiate contact or ask for help. Socioeconomic circumstances must also be considered (eg, access to transport or a telephone).<sup>139</sup> It has been reported for other health conditions that it is more effective to provide consumer information proactively, for example, using a range of media to provide consumer information and, in the absence of any evidence to the contrary, it should be assumed that the

same is likely to be true for ASD (*Recommendation 2.2.3*).

Conversely, teachers and other professionals need to recognise the value of the information held by parents and other family members/whānau. In addition to specialist assessments, it is essential that teachers and parents work together to develop an awareness of the child's specific strengths and difficulties. Understanding and interpreting this information is often the key to successful interventions and professionals need to find sensitive ways to gather this information from parents and highlight its importance.<sup>104 106</sup> (*Recommendation 2.2.2*).

As well as keeping parents and families well informed, parent education has been identified as one of the most widely accepted intervention methods for children with ASD.<sup>140</sup> It has been noted that assessment of factors likely to influence the success and course of intervention is in the early stages of development. An understanding of the key factors influencing the effectiveness of parents as teachers should help:

- aid choice of intervention and timing to optimise success
- identify parents who would profit from parent education
- identify barriers to accessing education and possibly increase maintenance of gains.

Two survey studies, each of over 250 mothers whose children were receiving early intervention, showed that the highest preference for services was for parent education activities. This preference rated higher than the preference for other family support activities, including personal/family assistance and resource assistance.<sup>141 142</sup>

Parent education is generally associated with improved family outcomes. Parent education increases the number of intervention hours that a child receives and has been shown to help children to generalise and maintain what they have learned, which reduces stress for parents.<sup>106</sup> In addition, the use of effective teaching methods for children with ASD results in more adaptive skills for the child, giving family and whānau members access to a wider range of leisure options and more time for one another.<sup>104</sup>

In order for parent education programmes to be effective, parents may first need support in other areas, such as respite care, vocational training, development of peer networks and counselling to deal with their own emotional and mental health issues.<sup>106</sup>

In summary, parent education should:

- be ongoing, for individual needs change according to the child's age and circumstances
- take a variety of forms (eg, face-to-face, distance, video and online)
- take into consideration family needs, such as work commitments and access to respite care
- include shared professional learning and development with professionals in the field to lead to a common understanding of needs
- take into consideration the needs of rural families and whānau (ie, distance education)
- consider cultural issues such as differing perceptions and management of disability and the impact of ASD on children's cultural development
- where possible, be available in the language of the participant family
- include services for siblings and other family members.<sup>11 104 106 116</sup>

## 2.3 Physical wellbeing

### Summary of recommendations

Recommendations	Grade
2.3.1 Individualised support should be available to people with ASD who require assistance to manage their physical wellbeing and health care.	C
2.3.2 Medical assessments should be comprehensive.	B
2.3.3 A health-assessment profile for people with ASD should be developed and medical and health care practitioners trained in its use accordingly.	B
2.3.4 The health-assessment profile should include: <ul style="list-style-type: none"> <li>• screening for mental health issues and the careful surveillance for emergence of epilepsy</li> <li>• age-related prompts for screening for hearing loss, eyesight changes/ glaucoma, hypertension and metabolic syndrome</li> <li>• dietary and exercise guidelines to prevent secondary health issues, especially for those on medication</li> <li>• screening for motor, sensory and perceptual difficulties.</li> </ul>	B
2.3.5 People with ASD should have regular health checks, especially if they have an intellectual disability or have ASD symptoms that may impair their ability to self-monitor or report potential health problems.	B
2.3.6 Medical and health care practitioners should take into account the symptomatology of their ASD clients/patients, and adapt their practices and procedures accordingly.	C
2.3.7 The dental needs of people with ASD in New Zealand should be investigated.  People with ASD should be provided with factual information on dental hygiene tailored to their cognitive level.  Dentists should alter their processes and procedures to take into account the symptomatology of their ASD patients.	B C B
2.3.8 The quality and quantity of sleep of people with ASD should be considered by health care professionals, and be addressed therapeutically.  Medication and behavioural treatment of sleep disorders should be considered.  The effectiveness of medication and behavioural treatment of sleep disorders should be further investigated.	B C C
2.3.9 Research should be undertaken to identify the needs of people with ASD with regard to constipation, allergies, medication reactions, menstruation and exercise.	C



Recommendations	Grade
2.3.10 In the absence of evidence for effective interventions to address specific health problems, help should be sought from suitably experienced health professionals.	C
2.3.11 All children with ASD 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 contention that this vaccine has a role in the causation of ASD.	A
2.3.12 The effectiveness of health-promotion campaigns with people with ASD should be investigated.  Health-promotion campaigns should ensure that people with ASD are included as a specific target group.	C  C
2.3.13 Recommendations on the health care of people with an intellectual disability should be implemented in relation to people with ASD who also have an intellectual disability.	B
2.3.14 Sensory issues in people with ASD should be identified and appropriately addressed by occupational therapists with experience in ASD. These assessments should lead to specific recommendations.	B
2.3.15 Methodologically rigorous research is needed to examine the effectiveness of current evaluation methods and treatments used to address sensory issues.	B

### 2.3.a Health needs

As described in Part 1 of the ASD Guideline, the health care needs of people with ASD can be complex. Not only do people with ASD have higher likelihood of epilepsy and other co-morbid conditions (see section 1.3: *Differential diagnosis*), but also the appropriate management of their health care needs is complicated by the impact of the symptoms of ASD itself.

For example:

- the level of social skills development that people with ASD have will affect their understanding of the roles of health care practitioners, their behaviour with the health care practitioner, their understanding of boundaries of the relationship and their ability to trust and thus disclose personal information
- communication difficulties can limit the information provided to the health care professional, the understanding that people with ASD have of their health care needs, and the explanations, instructions and advice given to them
- people with restricted and/or repetitive interests may not attend to health care needs at all, or attend to them inappropriately
- some individuals with ASD experience unusual sensory and perceptual sensitivities (both hypo- and hyper-responsivity) to a range of experiences including light, sound, taste, touch and pain
- there may be unpredictable reactions to medication, sleep disturbances, issues with diet and, for some people, engagement in behaviours that can be harmful to themselves.

In New Zealand, public sector health services focus on the provision of care in primary health settings. Everyone is encouraged to enrol with a general practitioner (GP). The health care of children known to have ASD is often monitored by a paediatrician in addition to the service provided by the general practitioner. However, specialist input usually ceases when the person reaches adulthood. As a result, it is possible that many adults with ASD access only GP care and do not access specialist services. Accounts by people with ASD suggest that there are barriers to good health care which include lack of attention to health issues, anxiety, poor communication and confusion and avoidance of contact caused by dissatisfaction with previous contact.<sup>33 143</sup>

Clearly, some people with ASD need support to manage their physical wellbeing appropriately, and medical and health care practitioners require knowledge of ASD and how it affects their clients to be able to provide optimum health care services (*Recommendation 2.3.1*).

Strategies to improve the current situation could include:

- comprehensive medical assessments of people with ASD<sup>11</sup>
- routine health care screening<sup>144</sup>
- the development of a health-assessment profile covering:
  - close surveillance for the development of mental health problems and epilepsy
  - age-related prompts for screening for hearing loss, eyesight changes/glaucoma, hypertension and metabolic syndrome
  - dietary and exercise guidelines to prevent secondary health issues, especially for those on medication

- screening for motor, sensory and perceptual difficulties
- education in ASD should occur both in initial and in post-qualification training of GPs, nurses and other health care practitioners<sup>144–146</sup>
- educating families, whānau and carers how to, first, support the person with ASD to attend to their own health care, and second, how to recognise health care issues and get assistance accordingly (*Recommendations 2.3.2, 2.3.3, 2.3.4, 2.3.5 and 6.8, Professional learning and development*).

Health care providers have also been advised to:

- work with the person and their family/whānau to ensure that their needs are understood
- work within the interests and strengths of the person with ASD
- alter agency procedures to take the ASD needs into account (ie, have several short appointments rather than one long one, use the same room each time, fit into their daily routines and use language they understand)
- communicate clearly
- use photographs or pictures to explain procedures
- provide visual and written information
- remove stimuli that may distress the person
- give feedback and encouragement<sup>33 47 143 146–149</sup> (*Recommendation 2.3.6*).

### 2.3.b Specific health care issues

#### Acute and emergency care

Acute and emergency medical care presents special problems for people with ASD and their parents, carers and families. The very nature of acute illness and the need for urgent medical care means that the child or adult cannot be prepared for the experience. Communication difficulties mean that the individual may not understand the need for unpleasant and invasive procedures, such as establishing intravenous lines. It is important that all health care staff have education in the special needs of people with disabilities, including ASD. Occasionally, sedation or even general anaesthesia may be required for procedures that could normally be carried out on fully conscious children or adults.

#### Dental hygiene and care

Some evidence exists suggesting that the oral hygiene of some people with ASD is compromised and that people with ASD have increased risk of caries and periodontitis.<sup>147</sup> The only preventative measure recommended in the literature sourced was providing information and explanations on good dental hygiene in a manner suited to people with ASD.<sup>147 150</sup>

Recommendations to manage problems occurring within a dental consultation include:

- dentists telling their clients what they are about to do, showing them the procedure, then doing it, rather than simply doing it straight off
- using short and clear instructions
- using positive reinforcement
- using sedation or restraint (an appropriate approved approach by a health professional with specialist

skills) to enable treatment and avoid more intrusive measures (after explanation and obtaining written consent)

- organisational changes to the office and appointment scheduling<sup>147 148 151</sup> (*Recommendation 2.3.7*).

#### Sleep disturbance

Research suggests that whilst sleeping problems are frequent in normally developing children, children and adults with ASD have significantly more sleep problems.<sup>152–154</sup> In particular, adults with ASD appear to have more difficulty falling asleep, report less sleep and sleep of poorer quality, feel more drowsy during the day, are more likely to fall asleep during free time and need longer periods of sleep at night.<sup>154</sup> Research has indicated that children with ASD exhibited the same range of sleep problems as their normally developing peers (eg, difficulty settling, night waking, early morning waking, and co-sleeping), but were more sluggish and disoriented after waking.<sup>152</sup> Treatment by medication or behavioural sleep management programmes or both has been assessed by research studies, but more research is needed<sup>152 153</sup> (*Recommendation 2.3.8, see section 4.4.a*). Standard sleep hygiene procedures may be appropriate to use before medication and other treatments.

#### Other health issues

Issues identified in the literature, but about which no reliable research was found, include constipation, allergies, medication reactions, menstruation and need for regular exercise.<sup>155–157</sup> There are examples in the literature of practical suggestions for the health care of people with ASD and advice should also be sought from suitably experienced health professionals<sup>158</sup> (*Recommendations 2.3.9, 2.3.10*).

### 2.3.c Immunisation for children who have an ASD

Immunisation is an important personal and public health issue. All the diseases for which immunisation is offered have the potential to cause serious illness, disability and death. A child who is immunised against a disease is much less likely to contract that disease than a child who has not been immunised. Children who have ASD may not cope with illness as well as their non-disabled peers. In particular, children with ASD (and their parents) find hospital admission very distressing. Immunisation helps to prevent illness.

Some parents feel that they do not need to get their child immunised, because they think that disease will be less prevalent in the community where many other children are immunised. This is true and is sometimes called herd immunity. However, the proportion of children in New Zealand who complete all their immunisations is not high enough to protect vulnerable members of the community who have not received immunisation, for whatever reason.

Parents have been particularly anxious about MMR vaccine (Measles, Mumps and Rubella). This vaccine is given at the age of 15 months in New Zealand.

In 1997, a group of workers studying gastrointestinal symptoms in children announced (at a press conference before publication of their work)<sup>159</sup> that they had found a link between the development of autistic symptomatology and the prior administration of Measles, Mumps and Rubella (MMR) vaccine. A number of large and well-conducted studies of whole populations have demonstrated that this claim has no basis in fact. The lead worker has subsequently been disciplined by the General Medical Council in the United Kingdom and has been shown to have had a financial conflict of interest. Expert international review panels (such as, in the

United States, the Institute of Medicine of the National Academy of Sciences), have examined all the evidence and concluded that there is no causal relationship between either thiomersal or MMR vaccine and autism.<sup>160–162</sup> A recent study from Japan, where MMR vaccine was withdrawn for reasons unrelated to the autism controversy, demonstrated that the incidence of ASD continued to rise in a cohort of children, none of whom received MMR.<sup>163</sup>

Infection with measles, mumps and rubella can cause significant problems in some children. All these viruses can cause encephalitis and permanent disability. This is very rare as a consequence of infection with the mumps virus and rubella virus, but devastating when it occurs.

The evidence strongly indicates that all children should therefore be immunised according to the New Zealand schedule. Parents should be reassured that there is no scientific evidence to support the hypothesis that the vaccine plays any role in causing ASD (*Recommendation 2.3.11*).

### 2.3.d Nutrition

Full discussion of the nutritional issues in children with ASD is outside the scope of the New Zealand ASD Guideline.

Some children who have ASD restrict their intake of food by refusing foods on the basis of smell, taste, texture and colour. Such children may be very sensitive to small changes in the food offered, such as changing a brand of, for example, bread. Children may also restrict their intake on the basis of how the food is offered, for example refusing to eat if the food is not presented on a particular plate, or if certain foods are touching on the plate rather than separated. Often these self-restrictions result in the child taking a very limited range of foods, resulting in concerns that the child's intake of essential nutrients (especially vitamins and trace elements) is inadequate.

In this situation, the child's nutritional state should be assessed by their general practitioner, paediatrician or a dietitian. Dietary supplements may be recommended. It is acknowledged that access to dietitians who have paediatric experience is limited.

Some parents choose to place their child on diets that eliminate certain proteins (especially gluten or casein or both). Parents should ensure that children on these diets also receive adequate intake of vitamins and trace elements, especially where the child also self-restricts that range of foods taken.

Resources for parents can provide some guidance on this issue.<sup>164–166</sup>

### 2.3.e Health promotion

The health and physical wellbeing of society in general is frequently targeted by national campaigns on smoking, obesity, driving, alcohol and drug abuse, sexual health and safety, occupational safety and so on. While no research was found which assessed the effectiveness of these campaigns for people with ASD, given their communication, cognitive and social characteristics, it is likely that effectiveness is less than optimum. Adapting national health campaigns in order to more effectively engage people with ASD and their families (eg, through use of visuals and web-based initiatives) and developing ASD-specific campaigns on health issues has been recommended internationally<sup>47 144</sup> (*Recommendation 2.3.12*).

### 2.3.f Issues especially relevant to people who also have an intellectual disability

The physical health of the population of people with ASD who are also intellectually disabled is a significant issue. Research into the physical health of people with an

intellectual disability found that many have ongoing and complex health needs (often unrecognised) combined with difficulty accessing health care without support and they were often dependent on others to recognise their need for health services.<sup>167 168</sup> Communication issues were linked with impaired assessment, diagnosis, ongoing care and the ability to fully inform patients.<sup>167 169</sup> Medical care of treatable, relievable or curable conditions was substandard or simply did not occur for some people with an intellectual disability. They were often over-medicated, treated with outdated medication and unable to access specialist review. The use of psychotropic medication in the absence of psychiatric diagnosis was high and associated with attempts to manage behaviour, without attending to the cause of the behavioural difficulties.<sup>144 167</sup>

Clearly, recommendations made on the health of people with an intellectual disability are of high relevance to people with ASD, many of who also have an intellectual disability. Recommendations from the National Advisory Committee on Health and Disability state that:

*The systemic neglect of the health of adults with an intellectual disability [should] be urgently addressed ... directing the Ministry of Health to ensure that primary health care providers are aware of the health needs of adults with an intellectual disability and have:*

- *clearly developed policies for access to services*
- *comprehensive health assessment tools for people with an intellectual disability*
- *appropriate staff education programmes, including peer review processes*
- *health-promotion material is produced that is directed towards and accessible by this population*

- *prescribing practices for this population are consistent with current New Zealand best practice guidelines*
- *directing the Ministry of Health to ensure that service provider contracts include recognition, and adequate funding and that the disability support role includes assistance for people with an intellectual disability to regularly access health care*
- *directing District Health Boards to examine access to their secondary and tertiary services for people with an intellectual disability, identify barriers and take active steps to minimise or remove them, and utilise their Disability Services Advisory Committees to provide ongoing monitoring of this<sup>167</sup> (Recommendation 2.3.13).*

### 2.3.g Sensory processing

Evidence confirms the existence of sensory and motor difficulties for many children with ASD<sup>104 170</sup> (see also section 3.2.c *Sensori-motor development*). Most of the research evidence on sensory processing difficulties is derived from studies on children and young people with ASD but may be relevant to older people with ASD as well. Autopsy studies and magnetic resonance imaging (MRI) studies support the notion that people diagnosed with ASD have differences in the parts of the mid-brain associated with movement, the regulation of movement and attention, the symptoms of which may have an impact on a person's ability to communicate and relate to others.<sup>171</sup>

People with ASD, their families and carers have observed disordered levels of sensitivity to visual, auditory, olfactory and tactile stimuli. Sensory disorders include a wide range of perceptual experiences, and can cause disordered temperature perception, pressure and pain thresholds,

food intolerance and dietary restrictions and aversive reactions to environmental materials and clothing. Sometimes faulty sensory processing can have negative consequences to health and wellbeing. Assistance to put strategies into place can help people to succeed<sup>172</sup> (*Recommendation 2.1.14*). Behaviours that indicate a need for evaluation include:

- clumsiness; frequently tripping or falling
- toe walking
- difficulty throwing or catching a ball
- unusual grasping patterns when writing
- poor fine or gross motor movement skills
- balance problems
- poor posture
- over- or under-sensitivity to sound, lights, smell or touch
- being unusually active or inactive
- difficulty calming
- frequently impulsive
- difficulty with social situations
- frequent headaches or stomach aches
- specific or general learning disabilities
- tendency to obsess
- often anxious
- poor eating habits
- passive or aggressive behaviours
- developmental regression.

Autistic-like symptoms common in blind children (but which also occur in non-autistic blind children) include room hugging, spinning themselves and spinning objects, self-stimulation, echolalia and the reversal of pronouns.<sup>173</sup> Some blind children fit the diagnostic criteria for ASD,<sup>174</sup> and can be identified using standardised ASD assessment tools, such as the Childhood Autism Rating Scale.<sup>175</sup> The literature suggests that teachers, family, whānau and carers of visually impaired people with ASD adapt their techniques to take into consideration the



dual diagnosis that the person experiences, adapt resources from both fields of work, and ensure that they recognise symptoms of each disorder clearly, rather than simplistically attributing behavioural or emotional problems to other causes (eg, poor parenting skills, impaired mother–child attachment).<sup>173 176 177</sup>

Behavioural similarities also exist between deafness and ASD, to the extent that hearing impairment is often suspected in children eventually diagnosed as having ASD. However, some people with ASD are hearing-impaired or deaf as well,<sup>178–181</sup> and ear infections occurred commonly in a sample of 190 children and adolescents with autistic disorder.<sup>181</sup> The DSM-IV<sup>21</sup> criteria and the Autism Screening Instrument have been used to diagnose ASD in deaf children.<sup>179 181</sup> Issues for the support of hearing impaired and deaf people with ASD are the same as those above for blind people.

### Assessments

Abnormal responses to sensory stimuli are so common that they are seen by many as cardinal symptoms of autism despite not being recognised in the DSM IV.<sup>140</sup> Sensory processing problems may explain some autistic behaviours and differences in cognitive processes may explain others.<sup>182</sup> Poor sensory processing functions can affect learning, play, work, socialisation, health and wellbeing. Low motivation to participate can be the result of medium-term memory, cognitive functioning difficulties and sensory processing disorders, which affect a person's willingness to embark on tasks because of previous negative experiences. It is important that these issues are identified and properly addressed because they affect how the child responds to the environment, whether in early intervention, home and school settings or in the community.<sup>183 184</sup>

Assessments and treatment should be carried out by therapists with appropriate experience in ASD.<sup>183</sup> Essential elements for a complete multidisciplinary assessment may include assessments to investigate unusual sensory responses, motor planning, coordination difficulties and self-care problems for the person presenting for diagnosis. Joint assessments are considered preferable. All professionals involved in a multiagency assessment for ASD should be experienced and knowledgeable about ASD and assessment should lead to specific recommendations<sup>11</sup> (*Recommendation 2.3.14*).

### Interventions

There is no consistent evidence that sensory-based treatments have special effects (*see also section 3.2.c Sensori-motor development*).<sup>96</sup> Additional studies are needed to document the unusual sensory processing features and motor functions and their relationship to broader behavioural and educational outcomes. Methodologically rigorous research is needed to examine the effectiveness of current evaluation methods and treatments/interventions being used by occupational therapists (*Recommendation 2.3.15*).

Special forms of occupational therapy are used to help people with ASD to overcome their isolation, progress developmentally, find ways of coping and gain a sense of self and relatedness to the world.<sup>185</sup>

Some experimental therapies, such as sensory integration therapy, are sometimes tried but there is insufficient evidence to recommend them as it has not been established scientifically that they are effective (*see section 4.5: Other interventions*).

## 2.4 Coordination of services

### Summary of recommendations

Recommendations:	Grade
2.4.1 A coordinated service should be provided to families and whānau and they should be supported to access services across sectors.	C
2.4.2 Family and whānau support services should be flexible and timely.	C
2.4.3 Families, whānau and service users should have direct involvement in planning and implementation of service provision.	C

Good Practice Point:	
2.4.4 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. This requires further discussion and analysis to support implementation of services.	✓

### Support and service needs

The complex range of emotional and practical difficulties that parents and carers of children with ASD experience tend to change over time.<sup>106 116</sup> These often unmet needs include:

- difficulties accessing diagnostic services
- anxiety and helplessness before diagnosis; sadness, anger and disappointment at diagnosis and, for some parents, a sense of relief in finding out what is wrong with their child
- difficulties finding and accessing services (particularly culturally appropriate services)
- lack of knowledge among medical, educational, social and community service agencies
- dependency issues and concern about the child's welfare in the years ahead
- intolerance, misunderstanding and lack of community acceptance of their child
- disruptions in family routines and lifestyle limitations, including reduced access to opportunities for social interaction, recreation and leisure activities
- heavy caregiving responsibilities and 'burn-out' from working intensively on behalf of their children
- unmet needs such as difficulty accessing respite care and advice about education and behaviour.<sup>186–189</sup>



To meet these needs it is helpful for families/whānau and carers to:

- have information on ASD and how it affects the person
- receive practical assistance, including preventative services and supports to minimise the need for crisis management
- have information on support services, ASD groups, rights and entitlements
- be familiar with services that are available and know how to access them (*Recommendation 2.4.1*)
- have their needs considered when a needs assessment is undertaken by the Needs Assessment and Service Coordination agency (NASC)
- know how to act as effective advocates for the child and family
- have one key person to case manage and liaise with the family and multiagencies
- know how to access emotional support and counselling, if required
- know how to access genetic counselling.

Family support services need to target families/whānau to increase their capacity to provide for a family member and develop informal and community supports around the family. Services should include flexible and intensive support, planned respite (if required), a range of planned short-term breaks, parent education and empowerment, home-based support, financial support, behavioural intervention, substitute care and transition services to adulthood<sup>190</sup> (*Recommendation 2.4.2*). Families of younger children especially need access to services and supports during school holidays.<sup>11</sup>

Many families and whānau report that mutual support networks are an important element in their support systems.

Individuals who have had experiences similar to their own can provide practical and emotional support. Professionals can play a role in providing information and facilitating parent entry into a support network.<sup>191</sup>

Many of the issues faced by carers are not inherent to the impairment of the person with ASD but are socially constructed.<sup>192</sup> Researchers advocate:

- joint funding, requiring agencies to work collaboratively in providing services
- more direct involvement of users and families and carers in planning and implementation of service provision (*Recommendation 2.4.3*)
- more extensive use of the social model of disability in applying welfare policies
- education and public information so that the public is more accepting of children with disabilities in the community.<sup>192</sup>

### Service coordination

The need for service coordination and case management for individuals with ASD is emphasised throughout the ASD Guideline (*Good Practice Point 2.4.4*). The heterogeneity of the condition of ASD (wide range of degree of impairment, age at diagnosis, intellectual ability, personal needs and health status) necessitates a wide range of supports and services. Needs Assessment and Service Coordination (NASC) is the first step for a person to get Government-funded disability support services.

[www.supportoptions.co.nz](http://www.supportoptions.co.nz)

The Health Funding Authority (previous funding body whose functions are now fulfilled by the Ministry of Health and District Health Boards) developed guidelines for needs assessment and services coordination agencies working with people with ASD and their families/whānau.<sup>193</sup> The Health Funding Authority Guidelines recognise that the nature of the needs of people with ASD increases the likelihood that they will need intensive service coordination, with follow-on benefits accruing from an ongoing relationship with their service coordinator. An individualised approach to planning and delivery is seen as particularly important for people with ASD.

Specific recommendations on the coordination of multiple services are outside the scope of the New Zealand ASD Guideline, but remain critical to the success of its implementation. A number of general principles have been identified by the workstream leaders to guide the process of service coordination and planning:

- the ASD coordinator role should carry authority, to ensure effective service outcomes
- services should be coordinated within and across sectors
- self-determination and person-centred/individualised plans should provide the basis for all coordinated planning services
- referral pathways should be clarified through Memorandums of Understanding between agencies and services
- support infrastructure should be developed nationally.

## Part 3

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### Education for learners with ASD

“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.”

## Part 3 Education for learners with ASD

This part of the New Zealand ASD Guideline deals with the range of assessments and interventions for children and young people with ASD in educational settings. It also covers strategies for supporting young people in secondary school and education sector organisations.

The principles behind effective education are outlined in terms of their relevance for the various domains of learning. Further information and guidance is provided in Appendix 7, Core elements of effective teaching. Educational programmes that incorporate some of the outlined principles are listed in Appendix 8, Educational interventions.

### 3.1 Approaches to teaching and learning in the early years

This section relates primarily to children below age five, the early childhood population in New Zealand. However, some of the literature surveyed included children up to seven years of age.

#### Summary of recommendations

Recommendations:	Grade
3.1.1 Services should not wait for the diagnostic process to be completed but should be available as soon as a significant developmental need is identified.	C
3.1.2 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
3.1.3 Decisions about the type of intervention and the degree of intensity should be informed by a skilled team and reflect the child's developmental stage, characteristics, teaching goals and family preferences.	C
3.1.4 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
3.1.5 Interventions should be monitored and evaluated on an ongoing basis. Where there is lack of progress over a three-month period, 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
3.1.6 Spontaneous communication, socialisation and play goals should be a priority.	A
3.1.7 Approaches should emphasise pivotal skills such as spontaneity, initiation, motivation and self-management.	C
3.1.8 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 at least 15 to 25 hours per week.	B
3.1.9 Planning for intervention and evaluation should always take into account not just the child, but also family and whānau variables and outcomes.	C
3.1.10 Families and whānau should be part of the team involved in the development of priority goals and intervention plans.	C
3.1.11 A child's educational programme should reflect the child's interests and the developmentally appropriate learning models for his or her age.	C

Good Practice Points:	
3.1.12 Specialist early intervention staff should provide education and support to families, whānau and early childhood teachers in how to provide structure and supports for children in their natural settings ie, home, early childhood facilities and community.	✓
3.1.13 The literature on educational programmes for young children should be reviewed.	✓

### 3.1.a The importance of early intervention

There is a growing body of evidence that good quality early intervention results in positive outcomes for children with ASD<sup>104 194–198</sup> (*Recommendation 3.1.1*). There is some evidence that children who participate in intensive intervention before the age of three have a significantly better outcome than those beginning after five years of age.<sup>104 197</sup>

Research into interventions for young children with ASD requires the overcoming of many challenges.<sup>63 104 195</sup> These include matching sample groups in such a heterogeneous population and controlling for a wide variety of other variables (eg, parents using other therapies or treatments outside the study programme and finding adequate instruments to measure progress).<sup>199</sup> Many factors make it difficult to compare and/or replicate results. For example, studies use different outcome measures to demonstrate progress (eg, IQ, school placement, adaptive behaviour or functional spontaneous language and generalisation).<sup>104</sup> Many of the published studies of early intervention programmes are from university model programmes of early intensive intervention. They tend to involve high staff ratios, occur in artificial or clinical settings and often use research funding. In the United States, many of the clinical programmes operate for the full year.<sup>104</sup> These characteristics provide a challenge in considering research findings for New Zealand practice where resources are scarcer and intervention tends to be largely confined to term times (*Good Practice Point 3.1.13*).

### 3.1.b Theoretical approaches to teaching and learning

There are an ever-expanding number of approaches for intervening with young children with ASD that have been reported in the literature. Apart from education programmes, there are other treatments which focus on aspects such as diet. In this section, the focus will be only on education-based approaches (*see Part 4 for a discussion of other approaches*). It has been suggested that most educationally based intervention programmes can be categorised as fitting within a continuum of approaches, with discrete trial training at one end and developmental (social pragmatic) approaches at the other.<sup>200</sup> There appears to be a trend towards comprehensive programmes which use elements of all the models.

The models can be characterised as:

- discrete trial training (DTT)/traditional behavioural approaches, for example, Lovaas Young Autism Project<sup>201 202</sup>
- approaches which draw on recent behavioural and developmental research, for example, Pivotal Response Training<sup>203</sup> and SCERTS<sup>TM204</sup>
- developmental (social pragmatic) approaches, for example, 'Floortime'.<sup>205 206</sup>

The approaches represent a continuum of different philosophies and outcomes. They differ on a number of characteristics such as: the degree of prescription of the teaching versus flexibility; whether the approach is adult- or child-centred; whether the emphasis is on 'response' or 'initiation'; the naturalness of the learning context; achieving generalisation; artificial versus natural reinforcers; and the role of typically developing peers.<sup>200</sup>

Programmes also differ in the outcomes they aim to achieve. At one end of the continuum are traditional behavioural approaches such as DTT, which is designed to remediate ASD with the desired outcome being 'recovery'. At the other end are the developmental approaches, which place greater emphasis on acceptance and adapting to the child, and which consider a good outcome to be for individuals to realise their full potential regardless of the extent of their ASD.

### Discrete trial training

Applied behaviour analysis (ABA) is a branch of behavioural psychology which, in its broadest sense, is defined as the study of observable interactions between humans and their environment. ABA includes a wide range of techniques. The focus in education has been to improve instruction so that it results in learning that makes socially important changes in students' lives.<sup>207</sup> One of the original techniques of ABA was DTT and this has resulted in some confusion over the use of the term ABA to only represent this single technique.<sup>196</sup>

DTT is an instructional technique in which a task or trial is isolated and taught to an individual by being repeatedly presented to them. Responses are recorded for each trial or command, and the trial is continued until the individual has demonstrated mastery.

The controversy that accompanies debates about ABA usually revolves around a few specific programmes which use traditional DTT methods, such as the Lovaas' intensive behavioural therapy<sup>201</sup> and other programmes that use similar principles. The controversy focuses on a number of issues: (1) skills of the therapists, (2) intensity of the programme and (3) lack of flexibility.

1. DTT programmes often rely on a non-educationally qualified 'therapist' following a pre-set programme. Although the therapist is trained in delivering the programme, researchers have questioned the appropriateness of one-to-one instruction with an individual who may not have the skills and knowledge to plan, implement and evaluate a programme using best practices for children with ASD.<sup>208</sup>
2. Traditional DTT methods specify a level of intensity for all children; this can become controversial for several reasons. First, each child is an individual and it is unlikely that the same levels of intensity will apply for each. Second, traditional DTT programmes have tended to take a more-is-better, follow-the-manual format which is not individualised. Third, a highly intensive programme is a costly programme, which tends to put funders and parents in conflict.<sup>208</sup>
3. Proponents of DTT-type behavioural programmes often advocate education for up to 40 hours a week in a one-to-one context to achieve 'recovery'. This is in conflict with the evidence that there is neither a cure for ASD nor a single educational technique that can or should be used exclusively to meet the needs of individuals with ASD. The most appropriate and efficacious programmes for children with ASD employ a variety of practices, including a systematic and ongoing

evaluation of interventions and treatments.<sup>11 104 199 200 209</sup>

### More recent developments in ABA

Many other ABA techniques have been developed, in some cases to address weaknesses in the early discrete trial techniques, such as generalisation. In contemporary ABA (which may involve incidental teaching, pivotal response training, naturalistic teaching and milieu teaching), there is a preference for carrying out interventions in naturalistic settings and involving the most appropriate or natural person for that setting. Usually, if goals are taught in a one-on-one situation in isolated settings, this is only for a very brief time with 'real-life' generalisation and maintenance being an important outcome.<sup>104 200 207 209 210</sup>

These ABA programmes, unlike traditional ABA approaches, sometimes start with adult-directed goals, but control is shared or shifted to the child as soon as possible. Initiation and spontaneity are important elements and teachers are encouraged to follow the child's lead and interests. Observations, functional assessments, naturally occurring events and developmental factors determine the next goals for the child.<sup>200</sup>

It has been advocated that, with appropriate training and support, the broader ABA principles can be adopted by parents, family, teachers and teaching assistants and used in both inclusive educational and community settings.<sup>209</sup>

### Developmental pragmatic approaches

Developmental pragmatic approaches advocate using the child's natural interests and motivations to re-establish the developmental sequence of communicating with and relating to others.<sup>211</sup> These approaches are the most recent of the three broad categories of approaches and have

not yet been fully evaluated. They have as their foundation the literature on cognitive, social and communication development. The context for learning is considered very important and activities and events are chosen for their interest and motivation for the child. Teaching may not be confined to a set time and an emphasis is placed on using a variety of social situations and routines.<sup>200</sup>

Researchers have identified a number of characteristics of the social pragmatic developmental approaches:

- focus on teaching spontaneous social communication
- emphasis on building multi-modal communication repertoires, for example, speech, gestures, augmentative communication
- control is shared and turn-taking encouraged
- learning is done within meaningful activities and events
- children are involved in a variety of social groupings
- child development sequences influence the development of goals
- visual and gestural supports are used to aid the child's understanding
- focus on helping the child to develop socially appropriate means to gaining some social control, for example, ways to protest
- emotional expression and affect are central to the development of relationships and learning.<sup>200</sup>

*(For a further description of the programmes mentioned in this section see Appendix 8, Educational interventions.)*



### 3.1.c Implications for practice

#### Which is the best intervention?

No one model has been shown to meet the needs of all children with ASD<sup>104 196 199 200 212 213</sup>. All the models have something to offer in certain situations. The skill of the professional is knowing when to use which model to meet the needs of particular children, situations and skills.<sup>197–200</sup> The most appropriate and efficacious programmes for children with ASD employ a variety of practices, including a systematic and ongoing evaluation of interventions<sup>11 104 199 200 211</sup> (*Recommendation 3.1.2*).

Young children with ASD can be expected to make significant progress when diagnosed early and exposed to structured, consistent approaches that are based on effective models and educational methods.<sup>199 210 211</sup>

#### What is known about the characteristics of quality intervention programmes?

A number of characteristics of successful programmes have been identified.<sup>104 194 210</sup>

##### 1. Making the earliest possible start to intervention

Early intervention services should be available as soon as a significant developmental difficulty is recognised, even if the full diagnostic process has not been completed.<sup>104 194 210</sup> Services should be provided in home and community settings as well as in early childhood education services according to the developmental needs of the child and family circumstances<sup>104 194 197 210</sup> (*Recommendation 3.1.1*).

##### 2. Individualising services for children and families and whānau

Individual plans should be developed for children who are identified as having specific ASD needs.<sup>194</sup> The development of plans requires access to a team of skilled, knowledgeable professionals who can work with the family and, where appropriate, early childhood teachers to assess the child in his/her usual setting and provide information and support to decide on goals to meet the child's needs<sup>210</sup> (*Good Practice Point 3.1.12*).

Research suggests that it is important that such individualisation incorporate the child's interests and motivations as well as developmental needs.<sup>104</sup> Developing and maintaining an individual profile for the child can help with this.<sup>11 200</sup>

Services and interventions should also match the needs, priorities, concerns and interests of families.<sup>194 197 210</sup> Professionals' knowledge of the family's current goals should be updated on a regular basis<sup>210</sup> (*Recommendation 3.1.3*).

##### 3. Providing systematic 'planful' teaching

Systematic goal-directed teaching needs to be carefully planned and have a strong conceptual base.<sup>194 210</sup> Optimal strategies may be different depending on whether a new skill is being taught or an existing behaviour generalised.<sup>63</sup> Those working with children need to be familiar with a range of interventions and in what circumstances they can be used appropriately.<sup>195 199 213 214</sup>

While adequate individual instruction is crucial to early learning, the greatest effect for children with ASD lies in the generalisation of that learning, which is achieved through working with early childhood education personnel and parents. Generalisation and maintenance need to be carefully planned and are more likely to be attained when skills are taught

in natural contexts and routines<sup>104 200 207</sup> (*Recommendation 3.1.4*). There is little long-term value in individual therapies unless the techniques are taught to and used regularly by the child and people who work with him or her in natural contexts.<sup>63 199 200 210</sup>

An important aspect of systematic teaching is ongoing evaluation and assessment.<sup>104 196 210</sup> Measures need to go beyond traditional cognitive and language skills and look at characteristics such as emotional development, motivation, social competence and functioning in natural environments.<sup>200</sup> There are many assessment tools and techniques. Learning Stories,<sup>215</sup> which is a narrative-based form of assessment and currently widely used in New Zealand early childhood education services, may be one useful technique to document these developments. However, for this to be useful for children with ASD, the observer needs to have a good working knowledge of ASD and how it affects the particular child being observed.<sup>215</sup> Whenever possible, observations and assessment are most effectively conducted in the child's natural environment.<sup>200 216</sup>

If a lack of progress towards goals is seen over a three-month period, consideration needs to be given to one or more changes such as in the degree of intensity through lowering child–teacher ratios, increasing time for instruction and practice, adapting the curriculum or intervention goals or providing extra consultation and support to staff<sup>104 210</sup> (*Recommendation 3.1.5*).

It is crucial that all staff have appropriate education and qualifications in ASD and have professional learning and development, opportunities and time to develop the skills and knowledge that early intervention teams need to be effective<sup>11 63 104 210</sup> (*Recommendation 6.18, Professional learning and development*).

#### 4. Providing a curriculum to meet the needs of the young child with ASD

Priority should be given to goals that emphasise functional spontaneous communication and social development, including play<sup>104 194 196 197 200 210 213</sup> (*Recommendation 3.1.6*). Other important areas relate to the enhancement of a child's ability to participate in and have some control over his/her environment.<sup>104 194 200</sup> Provision of proactive interventions for behaviour challenges, which usually involve teaching the child alternative skills and making environmental and learning adaptations, is another high priority.<sup>104 210</sup>

There is evidence that addressing 'pivotal' areas will have the greatest probability of positive effects in many areas of functioning.<sup>63 196 197</sup> Pivotal skills training<sup>203</sup> addresses teaching core areas of functioning such as improving motivation, responding to multiple cues, self-management and self-initiation of social interactions. This is in conflict with the notion of targeting many individual or narrowly defined behaviours<sup>196</sup> (*Recommendation 3.1.7*).

Some possible important pivotal skills that children need to function in the classroom or early childhood setting may include the abilities to:

- attend
- imitate others with understanding, not irrelevantly
- comprehend and use language/have a good communication system in place
- play appropriately with toys
- develop and apply cognitive skills appropriately
- interact socially appropriately with others.<sup>217</sup>

### 5. Intensity of engagement of the child

Intervention for the young child with ASD (ie, those below eight years) requires intensity, but the optimal amount of intensity for different children is still not determined.<sup>197</sup> Hours of intensive intervention do not necessarily equate to effective practice or improved outcomes. The quality of the intervention/education is at least as important as its intensity.<sup>196</sup> The intensity of an intervention is not synonymous with the number of teacher aide hours or the hours of attendance at an early childhood education centre. It may include time engaged with parents and other carers who are incorporating the goals for the child into family routines and play.

For typically developing children, providing an opportunity to participate in a developmentally appropriate activity is sufficient to have an educational benefit. For children with ASD, opportunities to participate are not always utilised by the child and it is suggested that educational opportunity is more appropriately measured, not by hours of attendance, but by hours of engagement<sup>63 194</sup> – although there is considerable debate about how engagement is defined.<sup>11 104 194 195 199 200</sup>

For the purposes of this guideline, a child is 'engaged' when he or she is focused on systematically planned, developmentally appropriate activities (either in the home or in an educational setting) leading towards identified objectives.<sup>104</sup> A more naturalistic model might define engaged time as any time in which the child is interacting and responding (rather than just being present) during activities such as:

- play sessions
- reading or sharing
- one-to-one parent–child time
- time in an early childhood education setting where the child is engaged in goals related to his/her individual plan

- activities such as shopping and bath time, where there is a deliberate intention to practice skills or engage in interactions.

Many different approaches may be used to achieve this intensity. The choice will depend on the goal, the developmental level of the child and the setting.

For children with ASD to make progress, they need to be engaged in developmentally appropriate activities or interactions for at least 15 to 25 hours a week<sup>11 104 194 199 217</sup> (*Recommendation 3.1.8*). However, individual decisions about intensity need to be made with consideration for the child's stage of development and family preferences and needs.<sup>63 104</sup> This engagement can occur in the home and community as well as in early childhood education settings. Early childhood teachers need education to understand that, for this group of children, the opportunity to participate does not of itself constitute engagement.<sup>104</sup>

There are resource implications in providing support for such intensity across a range of settings and with a variety of adults as teachers.

### 6. Sustainable family involvement

Planning for intervention and evaluation should consider not just child but also family/whānau variables and outcomes<sup>63 200 213</sup> (*Recommendation 3.1.9*).

Family-centred services are already a well recognised and important part of New Zealand early childhood education and this approach is to be supported and encouraged. Particular consideration needs to be given to how early intervention services can incorporate the cultural values of the family/whānau in developing individual plans.<sup>194 210 213 214</sup>

Families and whānau need to be part of the team involved in the development of priority goals and intervention plans (*Recommendation 3.1.10*). The family's perception that the goals chosen are socially valid is of the utmost importance.<sup>214</sup> If they wish, they should receive support and training so that they can incorporate the generalisation of skills into daily routines.<sup>104 194 197 210 213</sup>

### 7. Structured environments

A structured environment for young children with ASD is strongly recommended.<sup>104 194 200</sup> This structure can relate to both the physical and social environment as well as the instructional environment.

Early childhood education environments have an emphasis on social interaction and negotiation, which is the core difficulty for children with ASD. Teachers need education in how to provide structure within these environments (eg, the use of visual supports) (the importance of structure is explored more fully in section 3.2). Families may also need support and education in this area.<sup>104 210</sup>

### 8. Developmentally appropriate practices

Although children with ASD require certain areas of the curriculum to be emphasised with more intense teaching and learning opportunities, it is important that the activities and methods chosen are developmentally appropriate.<sup>104 194 195 213</sup> For the very young child, this often means learning through play and following their interests (*Recommendation 3.1.11*). Developmentally appropriate practice is an important tenet both in research and in New Zealand early childhood education services. Te Whāriki emphasises this point.<sup>218</sup>

### 9. Intervention in natural environments and with access to typically developing children

Best practice for children with ASD is not achieved by teaching in isolated settings away from other children and the quality of an intervention is at least as important as its duration.<sup>104 194 199 200</sup> Inclusion of children with ASD in regular settings is a common early childhood education practice in New Zealand, but the lack of structure and high noise levels in these settings may make it difficult for some young children with ASD to participate without careful planning. Both home and early childhood education settings are natural environments for young children, and services should be available in both, according to family preference and child need.<sup>194 200 216</sup>

### Links with Te Whāriki – the New Zealand early childhood curriculum

New Zealand is fortunate and unique in having an early childhood education curriculum. Te Whāriki (the New Zealand early childhood education curriculum) draws on an ecological perspective to highlight how the child's learning environments extend to incorporate family, whānau, community and professional relationships and settings. The strands of Te Whāriki are:

- wellbeing – mana atua
- belonging – mana whenua
- contribution – mana tangata
- communication – mana reo
- exploration – mana aotūroa.

These strands provide a very comprehensive framework within which goals for the young child with ASD can be developed in collaboration with families and whānau.

### 3.1.d Transitions and young children

The young child particularly requires structure at times of transition. Transitions occur when changing environments as part of the daily routine (eg, home to early childhood education centre), changing activities (eg, meal time to bath time) and when changing to a new education setting (eg, beginning school). These transitions require careful planning for both the child and the new environment.<sup>217</sup>

A key transition is to move from home to an early childhood education setting and from there to school. A survey has identified a number of successful programmes for young children with ASD. The following useful strategies have been suggested:

- preparing children to function as independently as possible from the beginning. This may begin by teaching imitation and attention to adults and then particular skills taught in small steps
- actively teaching ‘survival skills’, for example, turn-taking, sitting quietly during activities, listening to directions from both near and afar, communicating basic needs
- members of the team around the child visiting the new setting and considering the demands of the environment and teaching the child the skills needed, for example, putting belongings into a tray or locker, indicating they need to go to the toilet, putting toys away
- members of the team from the current setting providing information, support and education to the staff in the new setting
- planning the transition to the new setting with visits which take place on a gradual basis
- using social stories and other visual strategies to introduce the new setting and the people in it<sup>217 219 220</sup> (*see section 3.4 for a further discussion of transitions*).

## 3.2 Teaching specific curriculum areas in early childhood and school years

This section looks in detail at a number of different areas of curriculum for children and young people with ASD in educational settings and how they influence learning. It covers communication and literacy skills, social development, sensori-motor development, cognitive skills and self-management skills.

### 3.2.a Communication and literacy skills

#### Summary of recommendations

Recommendations:	Grade
3.2.1.1 Communication should be seen as a high-priority learning area, and communication goals should be included in individual plans for all children and young people with ASD.	A
3.2.1.2 The assessment and development of communication and social goals should complement each other. Teaching of the two areas should be carried out in parallel.	C
3.2.1.3 Encouraging initiations and spontaneous communication should be a key focus of intervention.	C
3.2.1.4 Interventions should take place in natural settings, using natural routines and natural consequences.	A
3.2.1.5 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
3.2.1.6 The communicative demands of the environment should be assessed.	C
3.2.1.7 Assessments should include the pragmatic aspects of communication.	C
3.2.1.8 Visual supports and technology should be available to support expressive and receptive communication and organisation according to the child or young person's individual needs.	B
3.2.1.9 Literacy instruction should be provided using multiple instructional strategies and building on the child's special interests.	B

Good Practice Point:	
3.2.1.10 All children with ASD should have an assessment and intervention suggestions by a speech-language therapist with expertise in ASD at a minimum of once a year, more often in early childhood.	✓

## Background

Communication is one of the most well-researched areas in ASD.<sup>104</sup> However, most of the research and evidence relate to populations of younger children (mostly 3 to 5 years old). There is very little research relating to school-aged children and those below age three. It is recognised that one of the greatest sources of stress for parents may be the communication difficulties of their child with ASD.<sup>197</sup>

Communication is a core difficulty for all children with ASD, but there is a wide diversity of skills among individuals. Impairments can range from a failure to develop any functional communication at all to the development of apparently good language, but with unusual elements.<sup>104 197</sup>

While research studies report that between one-third and one-half of children with classic autism do not develop functional language, this may not reflect the effectiveness of current interventions.<sup>104</sup>

The use of spontaneous communicative speech in children with ASD before the age of five indicates good prognosis for IQ, language, adaptive skills, and academic achievement in adolescence.<sup>104 197</sup>

Development of communication skills is also closely correlated with the development of social behaviour.<sup>197</sup>

Communication is a complex process and has several different aspects.

### 1. Receptive communication

This is the process by which messages from others are comprehended. Children with ASD have two core difficulties in this area:

- difficulties with auditory processing – receiving and making sense of auditory information
- problems with comprehension, including:
  - difficulties attaching meaning to words

- lack of prior experience, context or knowledge
- impaired understanding of facial expressions, body language and other non-verbal communication features
- inability to attend, or lack of interest
- a tendency to attend to environmental cues rather than attaining real understanding of verbal language
- a tendency to interpret statements literally.

### 2. Expressive communication

This describes the process by which information or messages are sent to other people. It includes:

- getting attention
- knowing what you want
- having a label or symbol for what you want
- using language, signing, pictures or other non-verbal communication strategies
- being able to use alternative or 'repair' strategies when not understood
- understanding the social and pragmatic rules that guide communication processes.

Joint attention, symbol use, imitation, developing conventional means of communication and understanding the social and pragmatic rules of communication are particular difficulties for children with ASD.<sup>63 104</sup>

### 3. Joint attention

Joint attention is the ability to coordinate attention between people and objects and is indicated by behaviours such as looking at people, drawing others' attention to objects and events to share experiences, following



the gaze or attention of another person and sharing emotions. Joint attention is regarded as a pivotal skill for communication and is considered to be a significant predictor of language outcomes compared with all other non-verbal indicators.<sup>104 197</sup>

#### 4. Symbol use

This involves learning to use conventional gestures and understanding and using the conventional meaning for words. It also includes learning to use objects functionally and in symbolic play. Children with ASD often find these skills difficult, but an understanding of symbol use is regarded as an important basis for communication.<sup>104 197</sup> Many children with ASD find visual quasi-symbols, such as photos and pictograms which are more static, easier to comprehend than verbal language.<sup>104 221</sup>

#### 5. Social pragmatic skills

Communication interventions have traditionally focused on unusual aspects of speech, such as echolalia (imitating the speech of others), pronoun reversal and unusual intonation. More recent research has emphasised the functional aspects and social or pragmatic aspects of communication, such as sharing attention (joint attention) or using and noticing non-verbal cues such as gestures and facial expressions.<sup>104</sup>

Children and young people who develop fluent speech may still have difficulty with social rules governing conversation.<sup>104</sup> Difficulties with prosody, which includes rate, rhythm, inflection and volume, also provide challenges which need to be addressed.<sup>222</sup>

#### 6. Echolalia

Children with ASD who learn to talk often use echolalia as they start to communicate.<sup>104</sup> Echolalia can be immediate (ie, an echo of something just

spoken) or delayed (ie, refer to an event in the past). This speech initially serves as a label for a particular situation but may at later stages serve a variety of communicative functions.<sup>223</sup> Many children eventually learn to break these scripts down into smaller, more meaningful chunks.<sup>197</sup> Even after children have developed more fluent speech, echolalia may reappear when the child is confused or fatigued.<sup>223</sup>

#### 7. Unconventional behaviours

Children who do not develop fluent communication skills may use inappropriate or unconventional behaviours such as tantrums, aggression or self-injury as means of communication. Improvements in communication have been found to be a key factor in improving and preventing problem behaviours.<sup>104 197</sup>

There is strong support for functional communication training – where the communicative function of a behaviour is identified and an appropriate communication form (including signs, visual symbols or language) is taught as an alternative to the challenging behaviour. This intervention has the advantage of teaching the individual to communicate, as well as reducing undesirable behaviours<sup>104 197 200 221</sup> (*this is discussed in more detail in section 3.2.e: Self-management skills and addressing challenging behaviour*).

#### Approaches to interventions

In the 1970s and 1980s, the developmental pragmatic literature which looked at the development of communication for social purposes began to influence interventions for children with ASD.<sup>200</sup>

Speech is only one form of communicating, but in the past it has been seen as the main focus for intervention for children with ASD.<sup>63</sup> However, without a good understanding of the social purpose of communication, the child may never make



use of the words they learn to communicate with others.<sup>200</sup>

Most children understand a lot about communicating before they learn to speak and it is equally important for children with ASD to develop this pre-verbal knowledge. Very young typically developing children begin to communicate using informal means such as gestures – for example, raising their arms to be picked up, or pointing. Young children with ASD may have a limited range or unconventional gestures for their communication. They are likely to use communication to regulate another person's behaviour, such as requesting something by taking someone's hand and leading them to the object, and they are less likely to use the more socially oriented functions such as pointing to draw another person's attention to something.<sup>223</sup>

### Implications for professional practice

The research strongly indicates that improving communication is a very high priority for children with ASD.<sup>11</sup> The assessment and development of communication and social goals should complement each other. Teaching of the two areas should be carried out in parallel<sup>104 200</sup> (*Recommendations 3.2.1.1, 3.2.1.2*).

One study reports success in teaching young children joint attention skills and symbolic play which generalised to playing with caregivers.<sup>224</sup>

There is increasing evidence for the importance of encouraging initiation and spontaneous communication<sup>197</sup> (*Recommendation 3.2.1.3*). A child's attempts to initiate will tend to result in others finding strategies to understand and communicate with them, which is likely to result in further positive initiations.<sup>104 197</sup>

The research increasingly emphasises the importance of interventions which take place in natural settings, within natural routines and which use natural consequences (*Recommendation 3.2.1.4*). These activities are often built on the child's interests.<sup>63 104 197</sup> Children will benefit from communication goals that are carefully planned and implemented by teachers and carers throughout the curriculum and throughout the day, rather than in one-to-one therapy sessions in a clinical setting on a more intermittent basis. Speech-language therapists will need skills in scaffolding teachers' and carers' learning to support such interventions<sup>197</sup> (*Recommendation 6.6, Professional learning and development*).

Interventions which emphasise the capacity to understand the purpose of communication rather than simply focusing on the form of the message (eg, learning to say words) are most important.<sup>63 104</sup> Children who learn speech and language out of the social context may become prompt-dependent in their use of language and fail to generalise their learning to other settings and partners.<sup>197 200</sup>

### Assessment and goal setting

The most functional and relevant communication abilities that children acquire emerge from self-generated and self-motivated goals. Assessment of the function or purpose of their communicative acts is as essential as an assessment of the means (words, informal gestures, pictures etc) they use to communicate their message. Consequently, effective assessments include observations in natural settings and in activities that involve peers and significant adults.<sup>223</sup>

Formal measures should always be supplemented by informal assessments which include observations across a variety of settings and activities, and interviews

with significant adults<sup>11</sup> (*Recommendation 3.2.1.5*). Aspects which need to be assessed include eye gaze, facial expression, the child's range of communicative functions and use of gestures.<sup>104</sup> When assessing immigrants and others where English is not their first language it is important that interpreters and translators are available.

The most effective communication assessments are those performed by members of a multidisciplinary team in conjunction with assessments of other aspects of development.<sup>11</sup> Consideration should be given to how these assessments relate to and influence each other, and goals based on these assessments need to be planned with the child's teacher and embedded in the child's day. An assessment of the communicative demands of the environments the child is in, as well as an assessment of the child, is required to do this effectively<sup>11 104</sup> (*Recommendation 3.2.1.6*).

For older children and "higher functioning" young people, assessments should include pragmatic aspects of communication such as their understanding of figurative language, ability to read the emotions and reactions of others and ability to communicate and understand abstract ideas<sup>225</sup> (*Recommendation 3.2.1.7*). It is also important to consider their ability to engage in conversation and repair breakdowns in communication.<sup>104</sup>

### Outcome measures

When evaluating the success of interventions, consideration should be given to increases in:

- the initiation of spontaneous communication  
The emphasis should move from simply measuring 'verbal behaviour' (eg, the ability to say words) to considering 'spontaneous communication' (ie, the ability to send a message to another person). Many children with ASD have

a tendency to become cue dependent if every effort is not made to encourage spontaneity.

- greater participation in functional activities  
An important goal for developing communication is an emphasis on skills which allow the child or young person to interact with many people and participate in a wide array of activities in a wide range of places.
- generalisation of communication skills across environments and partners  
Children and young people with ASD may not generalise new communicative skills with others unless this is specifically addressed. This generalisation should be encouraged across a variety of partners, places and events.
- conventional communicative means which are understood by a wider range of partners  
The emphasis on 'communication' acknowledges that there are many ways of conveying a message to another person. In the beginning, many idiosyncratic means may be used which only those who know the child well may interpret. A valued outcome is the use of increasingly conventional means. The ultimate aim of all intervention is increasing competence in the natural settings associated with the child's life.<sup>63 104 197 223</sup>

### Teaching strategies

#### 1. Use of augmentative communication

There is a considerable body of evidence to support the use of augmentative communication strategies with children and young people with ASD.<sup>11 104 219 221 226</sup> These strategies are used to support existing speech or as part of a multimodal system of communication which may include gestures.<sup>221</sup>

Augmentative communication interventions tend to suit the distinctive strengths and needs of children with ASD. These can effectively support both expressive and receptive communication. The most commonly used are those with visual symbols, for example, photos, pictures, objects or written words. They include:

- visual timetables
- schedules to outline the steps of a task
- rules or instructions in visual form
- communication boards or books.<sup>221</sup>

The rationale for their use includes the:

- strong visual processing of many children with ASD
- predictable and static nature of visual information
- close and obvious relationship of the picture to the concept it represents
- role such interventions may play in assisting children to rely on visual or symbol recognition to understand rather than relying simply on memory recall.<sup>104</sup>

Research suggests that aided symbol use (such as photographs, line drawings, symbols or written words) may enhance the development of speech in individuals with ASD. There appears to be no evidence that the use of augmentative communication strategies, in conjunction with language instruction, delays the acquisition of speech. This research includes those who are older than five years.<sup>104</sup> Two studies reported on the use of PECS (Picture Exchange Communication System) with children in the early childhood years and school-aged children. All students demonstrated an increase in speech and there was some evidence of generalisation to non-intervention settings.<sup>227 228</sup>

Using manual signs as augmentative communication are less often successful. They are often difficult for children to use

because of motor planning and motor imitation difficulties. However, manual signs used by others may be useful for some children to supplement their understanding.<sup>104 221</sup>

It is important to make a careful selection from the many resources available for the most appropriate intervention or device. Like all interventions with this population, careful assessment and planning is required. Consideration needs to be given to:

- receptive and expressive communication skills
- communication needs and desires
- cognitive skills
- sensory characteristics
- abilities of the communication partner(s)
- environments and their demands
- environmental barriers.<sup>221</sup>

Evaluation of the effectiveness of any resource needs to be done in a natural setting to ensure that its use has been generalised.<sup>226</sup> Use of visual supports and technology can effectively assist with this goal by supporting development of both expressive and receptive communication. Significantly, low-technology augmentative communication tools, such as picture systems, can be relatively simple and inexpensive to implement<sup>104</sup> (*Recommendation 3.2.1.8*).

## 2. Computers

While there is little research on specific computer programmes for individuals with ASD, there is some evidence that computer technology may enhance motivation, increase attention, and reduce challenging behaviour in individuals across the ability range.<sup>221</sup> Computer-based schemes are seen as particularly valuable for literacy development.<sup>219 229</sup>

### 3. Literacy skills

In the past, despite demonstrating skills directly related to literacy, some children with ASD have been labelled as too cognitively impaired or not ready for literacy instruction.<sup>230</sup> There is some evidence of situations where individuals without verbal language skills have learnt to read and write.<sup>230</sup> Often children and young people's interests have been dismissed as 'stimming' (self-stimulatory behaviours) when they could have been used to channel the students into activities enabling them to read, write, draw and communicate about their special interest or obsession (eg, trucks), at least until the interest wanes and drifts into another.<sup>230</sup>

Some children with ASD have hyperlexia, which is being able to read words beyond what would be predicted on the basis of cognitive and language scores. This often presents as early (at age 2 to 5 years) compulsive or indiscriminate reading of words, which develops in the absence of direct instruction. The decoding skills of these children appear to outstrip their understanding of the text. Research shows that hyperlexia in ASD tends to be associated with general receptive language difficulties rather than with reading comprehension per se. This is often combined with a lack of background knowledge about the topic due to their restricted experience of the world. Children with ASD are capable of learning to

understand what they read, but it should not be assumed that they can comprehend all the words they are able to decode. Hyperlexia occurs in children with a wide range of disabilities, but disproportionately in children with ASD (up to 10%).<sup>221 230</sup>

Most children and young people will benefit from literacy instruction that incorporates multiple instructional strategies to teach skills such as decoding, analogy, prediction and sight words<sup>230</sup> (*Recommendation 3.2.1.9*).

Research into teaching literacy to children with ASD is inconclusive, but emerging themes include:

- some children with ASD can sight-read words without teacher-directed rote drill
- interventions that use recommended practices for children without disabilities are also useful for children with ASD
- literacy-rich early childhood education service environments can promote literacy learning.

The recommended intervention is a balanced one that incorporates all the processes that are known to be involved in successful literacy learning.<sup>221</sup>

### 3.2.b Social development

#### Summary of recommendations

Recommendations:	Grade
3.2.2.1 Social assessment should be carried out in a variety of natural settings with both adults and peers as social partners.	C
3.2.2.2 Goals should be functional and consider family and whānau preferences.	C
3.2.2.3 Social interventions should take place in natural settings and within natural activities as much as possible. <sup>1</sup>	A
3.2.2.4 Interventions using carefully trained and supported typically developing peers should be encouraged.	A
3.2.2.5 All social intervention plans should include generalisation and maintenance strategies.	A
3.2.2.6 Support and training should be provided to families (including siblings) and whānau to develop social skills interventions in the home.	C

Good Practice Point:	
3.2.2.7 Socialisation goals should be included in all individual education plans.	✓

#### Background

Social difficulties are one of the core impairments for children with autism.<sup>102 104 216 231 232</sup> Social challenges may appear in the first few months of life.<sup>216</sup> One of the earliest signs is a lack of normal response to physical contact.<sup>231</sup> Studies show, however, that children with ASD tend to have standard attachment patterns with their parents or carers.<sup>104</sup>

The social interactions of children with ASD are characterised by low rates of both initiations and responses. This includes non-verbal communication such as gestures and facial expressions as well as verbal interactions.<sup>104</sup> This difficulty is most marked in interactions for the purpose of sharing experiences and establishing a joint focus of attention, rather than in initiations to have needs met and continue pleasurable experiences.<sup>104 233</sup>

<sup>1</sup> Research on social skills groups for young people and adults was comprehensively updated as part of the living guideline process. It is summarised in Appendix 10.6, and is available as full text from the Ministry of Health website.<sup>17</sup> (Also see new recommendation 4.2.1a, and new good practice points 4.2.1b and 4.2.1c in Chapter 4.)

Children with ASD have significant difficulties in relating to peers, using non-verbal communicative behaviours, imitating (actions, movements and vocalisations), and using and understanding symbolic or dramatic play.<sup>216 231</sup> They pay less attention to other people's emotions and tend to demonstrate fewer acts of empathy or shared emotion than do children who do not have ASD.<sup>104</sup>

As the nature of the communication impairments has been more accurately researched, it has become easy to see that social competence is closely related to impairments in verbal and non-verbal communication.<sup>231</sup>

Research has identified subgroupings of children on the basis of their social responsiveness: passive (few initiations but positive responses), aloof (indifferent in all situations, particularly with other children), 'active but odd' (seeks out interactions but uses odd language, focuses on obsessional topics and lacks understanding of others) and 'over formal and stilted' (excessive formality and difficulties with the subtleties of social situations).<sup>104</sup> These groupings can be useful to help focus interventions and set priorities.

Lack of speech does not prevent the development of increased social skills, but social interactions do require communication to initiate and respond, which underlines the importance of matching interventions to the child or young person's communication skills.<sup>104</sup>

Explicit teaching of social behaviour needs to be part of the individual plan for any child or young person with ASD throughout his or her life.<sup>210 216 232</sup>

### **Verbal and “higher functioning” children and young people**

Despite their command of language and sometimes their desire to interact, “higher functioning” children and young people with ASD are often unable to use their verbal skills to successfully enter the social fray.<sup>232</sup> These children tend towards repetitive enactments of solitary routines around their obsessive interests and either avoid social play or approach peers in ways that are unlikely to be reciprocated.<sup>233</sup>

Older children and young people have difficulty with peer relationships and demonstrating social and emotional reciprocity.<sup>234 235</sup> Social difficulties are thought to be a reason for the high rates of depression, which are often seen in “higher functioning” adolescents.<sup>232 236</sup> In adolescence, young people begin to engage in social interaction primarily by conversation and this provides many challenges for the young person with ASD.<sup>232</sup>

### **Approaches to interventions**

Interventions to enhance social development need to be carefully planned and systematic.<sup>237</sup> Particular care should be given to planning for generalisation and maintenance.<sup>104 216 238</sup> Practitioners need to be fluent in a range of approaches so that they can choose what is most appropriate for the teaching of specific skills and for particular settings. It is also important to match the approach to the developmental level and needs of the particular child.<sup>104</sup> Researchers advocate that it is important for teachers and other professionals to draw on their own theory of mind to try and appreciate their student's view of the world when planning interventions.<sup>233</sup>

## Implications for professional practice

### Assessment

Different aspects of socialisation require different forms of assessment.

#### Areas to be assessed

Because communication is the process by which people carry out social relationships, social and communication assessments and the goals and objectives that follow need to be considered hand in hand.<sup>104 238</sup>

Play is an important social activity for children; therefore, play skills also need to be assessed.<sup>104</sup> Researchers recommend an assessment of the sensory preferences of very young children.<sup>237</sup> These data will allow teachers and practitioners to more efficiently predict the features of toys which will be the most reinforcing. The interests and preferences of all children and young people will need to be understood if activities and materials are to be motivating.<sup>210 232 238</sup>

#### Assessment techniques and tools

Developmental scales may also be useful for assessing general social development. However, children with ASD often do not demonstrate typical patterns of development.<sup>104</sup>

Many researchers report that the ability to carry out targeted observations is a key skill for practitioners.<sup>231 233 239</sup> Observation allows information to be gathered on unusual forms of expression of needs and emotional states which may be missed by other forms of assessment.<sup>233</sup> Observations need to include the child's actual behaviours, including:

- initiations
- responses
- length of rounds
- interest in others
- proximity to others.<sup>104</sup>

However, data on the behaviours of the child alone are not sufficient. Observation should also include the reciprocal nature of social interactions, that is, who does what and with whom and the effect of this on social interactions. The degree of responsiveness and the skill of peers are also important aspects of the assessment and planning of the intervention.<sup>239</sup>

Observations using the type of narrative assessment with which early childhood teachers in New Zealand are familiar (such as Learning Stories) might be a useful tool for analysing social learning repertoires and interactions with peers. A range of settings should be used for assessment.

Social assessment should be carried out in a variety of natural settings (such as classrooms, community settings and homes) and should include both children and adults as interactive partners<sup>104 216</sup> (*Recommendation 3.2.2.1*).

### Goal setting and outcome measures

Social goals need to be very carefully designed and implemented and should form part of each child's overall education plan (*Good Practice Point 3.2.2.7*). Early goals for interacting with adults need to include joint attention, turn taking, imitation, responding to gaze, initiating social interactions and engagement with toys.<sup>104 237</sup> Encouragement to play in or nearby similar activities as peers and share materials, as well as to watch and imitate the gross motor actions of other children, are also important goals.<sup>237</sup>

Goals for school-aged children may include communication, participating in classroom routines, responding to adult directions and expressing needs. Goals for peer interactions might include what are sometimes called 'play organisers' – suggesting play ideas, sharing affection, assisting others and responding to initiations from peers. These are based on



the characteristics of socially successful children.<sup>104 239</sup> Social understanding of routines and other social events needs explicit teaching and should be given equal importance to the teaching of the skills themselves.<sup>240</sup>

Goals need to consider family and whānau preferences and be functional in the present setting or in the next environment which the child or young person will enter<sup>104 226</sup> (*Recommendation 3.2.2.2*). Functionality is defined as accessing control of the child's or young person's environment, increasing independence and quality of life and increasing performance.<sup>226</sup>

### Teaching strategies

Interventions to develop social skills in young children tend to come from two broad approaches to teaching: developmental and behavioural.<sup>104</sup>

Developmental approaches fit easily into early childhood education settings. These approaches tend to be child-centred in which the adult follows the child's lead and then attempts to stimulate and continue interactions. An example of such an approach is Greenspan's DIR/ 'Floortime'.<sup>241</sup> Many of these interventions are carried out in natural settings and use natural routines and activities.

In traditional behavioural approaches, the emphasis is on building skills by using one-to-one instruction. These approaches are more difficult to fit into child-centred early childhood education settings. Teaching tends to be adult-directed instruction of specific components, such as responses to gestures, toy play skills and social speech.<sup>104</sup> These techniques, with their emphasis on compliance, often do not acknowledge the child's initiations and often do not generalise to other settings.<sup>233</sup>

Some of the newer behavioural approaches, such as pivotal response training and incidental teaching, have elements of both approaches: encouraging child initiations and teaching in natural settings and routines while maintaining systematic teaching procedures (*Recommendation 3.2.2.3*). These approaches are more easily accommodated in early childhood education settings and have proven to be effective.<sup>104 210 226 237</sup>

### Instructors

Interventions can also be classified by the person who instructs the child or young person and encourages and prompts interactions and new skills.

#### 1. Adult-child interventions

##### Individual interventions

These can be adult-directed behavioural approaches which focus on specific skills, or more child-centred developmental approaches.<sup>104</sup> The focus of these is usually one-on-one. If a one-to-one intervention has been used to work on specific skills, it is important the child then has access to a group and is supported to generalise the skills learnt.<sup>216</sup>

##### Social skills groups

Social skills groups are a common intervention technique. They are often used with "high functioning" children and young people who have language skills. They rely on teaching and practising topics such as body language, emotion recognition and understanding and conversational skills in a group of target children. Teaching strategies include lessons, group games, conversations and field trips.<sup>210</sup>

Studies have shown good participant and parent satisfaction, but only modest improvement in target social skills. However, there is some evidence to suggest that they may, in fact, improve the participant's mood and self-image.<sup>210</sup>



Research on social skills groups for young people and adults was comprehensively updated as part of the living guideline process. It is summarised in Appendix 10.6, and is available as full text from the Ministry of Health website.<sup>17</sup> (Also see new recommendation 4.2.1a, and new good practice points 4.2.1b and 4.2.1c in Chapter 4.)

## 2. Peer-mediated techniques

Peer-mediated techniques are the best developed and most studied of all the interventions.<sup>210 216</sup> These techniques involve trained peers, usually without disabilities, prompting and sustaining social engagement.<sup>104 216</sup> These techniques have the advantage of not requiring the child with ASD to generalise from an adult instructor to peers.<sup>210</sup> Typically developing peers are taught to initiate such skills as ‘play organisers’ – sharing, helping and using praise and affection.<sup>104</sup>

Peer mediators need to be friendly, outgoing and skilled, and their preparation and support is important. Instruction, feedback and role play are important elements to use when preparing peers.<sup>231</sup> Interventions work best when several mediators are used, so that each target child has repeated opportunities to interact with a number of skilled peers.<sup>232</sup> Support and training for the education professionals who will be involved in developing peer-mediated programmes is also required (*Good Practice Point 6.25, Professional learning and development*).

Many of these peer-mediated interventions tend to be rejected by teachers because they are seen as being unduly complex and time consuming.<sup>232</sup> However, simpler peer-based approaches, such as ‘Stay, Play, Talk’, show promise with younger children and are easier to set up.<sup>232</sup>

The effectiveness of peer-mediated strategies has been demonstrated in many studies where interventions were well

planned.<sup>104 210 216 239</sup> (*Recommendation 3.2.2.4*). However, even when using well-trained peers, initiations and responses were not always maintained when the peer trainer was not present.<sup>210 216 231</sup>

### Circle of friends

This programme involves a group of students undertaking to provide support to the child with a disability. This programme has been shown to be inadequate on its own without ASD-specific education and support for peers.<sup>232</sup>

## 3. Combination of strategies

Some successful interventions combine both individual child-focused interventions and peer-mediated interventions to prompt and reinforce the strategies already taught.<sup>216</sup> These combined strategies have shown positive results as well as promising outcomes.<sup>104</sup>

### Setting for interventions

Interventions are most effective if they take place in natural settings and within regular routines and activities and involve opportunities for interactions with typically developing peers.<sup>104 216 232 238 239</sup> The social competence of peers has been shown to be a major factor associated with improved outcomes.<sup>210</sup> However, simply placing children and young people in settings with socially more competent peers will not be sufficient to foster social interaction without other intervention.<sup>216 232</sup>

The context for instruction needs to be developmentally appropriate.<sup>232</sup>

### Young children

An accepting and secure play environment, set up to encourage interaction with enticing toys and equipment, needs to be provided for young children.<sup>233</sup> Toys and activities need to be chosen with consideration for the child’s interests and preferences.<sup>237</sup> The arrangement of the environment can be used to prompt and

support social interaction. For example, desirable equipment can be visible but not accessible without interacting with another person.<sup>216</sup>

#### *Older students*

School-aged children and young people require appropriate games and buddy systems.<sup>232</sup> One study reported that the most effective activities for encouraging peer interactions are rule-governed games and construction materials, with dramatic and functional play the least effective.<sup>210</sup> However, another study reported positive outcomes from teaching symbolic pretend play. The intervention involved video feedback and observation and gradually reducing the amount of structure provided by the teacher.<sup>242</sup> Teenagers respond best to discussion groups on a variety of topics and social network interventions. Both interventions should include peers who are supported by adults and, where necessary, trained.<sup>232</sup>

#### *Other considerations*

Interventions to enhance social interactions need to be carried out in conjunction with communication interventions.<sup>104</sup> Social interactions with both adults and peers need to be targeted.<sup>104</sup> There is a greater likelihood of social interactions occurring in preferred activities which have a structure and are predictable.<sup>216</sup>

#### *The hidden curriculum*

Children and young people with ASD will need to be taught the unwritten rules of school life, such as what to do where, when and with whom. These rules have a tendency to change depending on the circumstances and children and young people with ASD will not usually be able to generalise what they have learned to different situations. Even “high functioning” students with ASD will probably not understand things that others may know intuitively.

Children and young people may need a great deal of support and direct teaching to master any of these skills:

- the meanings of facial expressions
- rules about personal space and touching
- the meaning of gestures and postures
- metaphorical language
- rhythm and time
- personal hygiene
- different ways of addressing people
- formal and informal language
- the meaning of common similes and metaphors to reduce over-literalness.

Strategies for teaching these skills might include the use of photographs and video, role-playing, acting skills, drama, cartoons or social stories.<sup>104 240</sup>

#### *Generalisation and maintenance*

The teaching of skills by themselves will seldom be effective if generalisation to other settings and people is not actively addressed<sup>236</sup> (*Recommendation 3.2.2.5*). Interventions need to be available throughout the day and in a variety of activities.<sup>216</sup> Where generalisation occurs, it is often attributable to high levels of peer responsiveness; therefore, peers need to be primed and supported to recognise and respond to interaction attempts.<sup>239</sup>

Other interventions which have anecdotal support

#### *Social stories*

‘Social stories’, developed by Gray and Garand, is a relatively new intervention<sup>243</sup> (see also *Appendix 8, Educational interventions*). Social stories are narratives written by adults about difficult social situations to help the child’s understanding. These stories help promote self-awareness, self-calming and self-management.<sup>240</sup> Only a few small studies

have been undertaken; one showed a decrease in the frequencies of inappropriate behaviours and anxiety levels and another showed an increase in social skill levels.<sup>232 244</sup> Other studies have demonstrated the utility of this intervention for increasing sharing, play and appropriate independent social initiations and responses, as well as for reducing aggression. Social stories probably need to be used in combination with other strategies.<sup>226</sup> There is a need for further research to consider which children and young people will benefit from such approaches.<sup>245</sup>

#### *Other interventions*

Other techniques that have been shown to be useful for improving social skills include:

- visual cueing – printed cues in work schedules to stimulate social initiations to other peers with ASD
- social games – teaching socio-dramatic scripts or games revolving around a child's special interest (both interventions increased peer interactions in multiple ways)
- video modelling – some studies have shown better skill acquisition of maintenance and generalisation than for in-vivo teaching techniques
- acting lessons – learning to express emotions verbally and non-verbally and interpret the feelings of others
- self-esteem building – from placing the child in the role of tutor or helper (eg, the teacher compliments the child and teaches him/her to compliment him/herself)
- social autopsies – conversations with adults which review and interpret social situations which have happened
- cartooning – the use of cartoon drawings to understand social situations.<sup>210 232 240</sup>

#### *Other issues*

##### *Interventions for home settings*

Without family/whānau involvement, interventions are unlikely to generalise to home and community settings.<sup>237</sup> Several studies have shown measurable improvements from simple interventions such as teaching parents and siblings to imitate a child in play with toys and other play skills on a daily basis, or daily early childhood education service programmes with positive child–adult interactions and play.<sup>104 226 231</sup> Support and education should be provided for families and whānau to facilitate the use of home-intervention strategies (*Recommendation 3.2.2.6*).

Strategies can include:

- rehearsing scripts
- videotaping conversations, reviewing and coaching
- structured 'play dates' (social opportunities with peers usually conducted within the home)
- structured conversations
- involvement in groups around a special interest.<sup>210</sup>

Siblings can also be involved in home interventions using many of the peer-mediated techniques.<sup>210</sup>

### 3.2.c Sensori-motor development

#### Summary of recommendations

Recommendations:	Grade
3.2.3.1 Teams should consult appropriate expert professionals such as occupational therapists for guidance about strategies to support children and young people whose sensory processing difficulties interfere with their educational performance.	B
3.2.3.2 Sensory programmes and strategies should be monitored carefully and discontinued if some progress is not apparent in 6 to 12 weeks.	B
3.2.3.3 Environments and tasks should be adapted to minimise negative sensory reactions, perceptual distortions or motor difficulties.	C

#### Background

Most children with ASD experience sensory and motor difficulties at some point in their development.<sup>104 183 246</sup> At present these are not included as part of the diagnostic criteria in either the DSM-1V or ICD-10. These difficulties include under- or over-reactions to basic sensations and perceptions (including touch, taste, sight, hearing and smell), movement and information from muscles and joints (proprioception). These difficulties are manifested early in the child's development (by 9–12 months in some reports).<sup>104 183</sup> There is evidence that sensory responses change with maturation. As with other aspects of development for this population, there is an uneven and fluctuating variation of difficulties for each child<sup>183</sup> (*see also 2.3.7 Sensory processing*).

Unusual sensory responses have been reported in various studies in 42 to 88% of older children with ASD. These include:

- hypo- or hyper-responses
- problems modulating arousal
- preoccupations with the sensory features of objects
- perceptual distortions
- paradoxical responses to stimuli.<sup>183</sup>

There is some evidence that auditory processing difficulties are a particular problem; in one study, these were demonstrated by all the subjects.<sup>183</sup> Visual-spatial skills appear to be more advanced than other skills, although individual differences are apparent.<sup>183</sup>

Behaviours may be associated with the need to seek or avoid sensory input or with difficulties in modulating sensory input to maintain attention and arousal appropriate to the demands of the task and environment.<sup>104 246</sup>

Although motor skills are generally more advanced than language or social skills in children with ASD, motor problems can be significant. Gross and fine motor skills such as gait, ball skills, balance, dexterity, motor imitation, handwriting, cutting with scissors, and sense of rhythm may be delayed. Children may demonstrate low muscle tone, oral motor problems, repetitive motor movements or motor planning difficulties (dyspraxia).

Research suggests that such children with dyspraxia may have more difficulties with the planning or preparation of movement than with the actual execution of the movement.<sup>183</sup>

### Approaches to interventions

A systematic review of the efficacy of sensory and motor interventions for children with ASD identified different types of interventions:<sup>183</sup>

- remedial interventions, ie, ones that target specific sensory motor components, for example, sensory integration and later developments such as sensory diets, visual therapies and Irlen lenses
- task and environmental modifications.

Some of the interventions reviewed have questionable rationales for using with children with ASD and no evidence is provided to evaluate their efficacy with this population. Many of the studies fail to directly link changes in the dysfunctional mechanism as a result of the remediation programme to functional changes in behaviour, for example, auditory sensitivity, visual distortions and vestibular dysfunctions. Generally results were inconsistent and changes were modest. It was concluded that this does not necessarily imply that the interventions are ineffective in all cases, but that there is insufficient sound research to demonstrate their efficacy. In some cases, it was difficult to tell whether benefits were from an intervention or from learning skills associated with the intervention (such as play-coaching, structured teaching and attention skills).<sup>104 183</sup>

Given the variability in developmental profiles of children with ASD, it has been suggested that the indiscriminate use of any sensory or motor-based programme is unwise, so a conservative approach to suggesting specific sensory or motor programmes is recommended. Good

practice suggests that decisions are best made on an individualised basis by expert professionals.<sup>183</sup> An expert professional would be someone such as an occupational therapist or physiotherapist who has ASD-specific education and experience in sensory and motor difficulties (*Recommendation 3.2.3.1*).

Interventions should be provided in short-term increments, progress should be systematically documented and the intervention should be discontinued if some progress is not apparent within 6 to 12 weeks (*Recommendation 3.2.3.2*). As with other interventions, best practice suggests that interventions are most effectively integrated into daily routines within naturalistic contexts to increase retention and generalisation of the skills.<sup>104 183</sup>

It has also been suggested that task and environmental modifications to address sensory issues and teaching compensatory strategies are useful in combination with other educational programmes<sup>183</sup> (*Recommendation 3.2.3.3*).

*(Other sensory motor interventions such as sensory integration are discussed in section 4.5. Music therapy and art therapy are discussed in Appendix 8.)*

## Implications for professional practice

### Assessment

Sensory challenges and preferences can be assessed by observing children and young people in their natural environments (home, school and community) and by using interviews and sensory checklists. Some children will need a more specialised assessment by an occupational therapist, such as a sensory profile which is based on parent report. This should still be used in conjunction with observation data and other measures.<sup>184 246</sup> Some of the following may be observed in children and young people with sensory issues.

**Table 3.1: Sensory stimuli and their possible effects on children and young people with ASD<sup>247</sup>**

Sensory system	Description	Some behaviours that might be observed
Vestibular	Movement of body in space	<ul style="list-style-type: none"> <li>• Motion sickness</li> <li>• Fear of heights</li> <li>• Avoidance of balancing activities or participation in sports</li> <li>• Seeking fast-moving activities</li> <li>• Engaging in frequent spinning, bouncing or running</li> <li>• Seeming oblivious to the risks of heights or moving equipment</li> </ul>
Tactile	Provides information about factors such as touch, pressure, texture, hard/soft, sharp, dull, heat/cold, pain	<ul style="list-style-type: none"> <li>• Avoidance of touch contact</li> <li>• Disliking and avoiding messy play</li> <li>• Disliking having hair brushed or washed</li> <li>• Appearing irritated by certain clothing and food textures</li> <li>• Appearing irritated by others' proximity</li> <li>• Appearing fidgety or active</li> <li>• Using hands to explore</li> </ul>
Proprioceptive	Provides information about where a certain body part is and how it is moving	<ul style="list-style-type: none"> <li>• Enjoying rough-and-tumble play</li> <li>• Relaxing when given firm touch or massage</li> <li>• Exerting too much or not enough pressure while handling objects</li> </ul>
Visual	Provides information from the eye about objects and people	<ul style="list-style-type: none"> <li>• Discomfort in strong sunlight</li> <li>• Sensitivity to television/computer screens or changes in lighting</li> <li>• Enjoying flickering objects (eg, computer, flicking pages, flickering hands)</li> <li>• Focusing on shadows, reflections or spinning objects, lines, patterns</li> </ul>
Auditory	Provides information about sounds in the environment	<ul style="list-style-type: none"> <li>• Becoming upset at loud or unexpected noises</li> <li>• Humming or singing to screen out unwanted noise</li> <li>• Unusual responses to voices</li> <li>• Dislike of large indoor spaces</li> <li>• Fleeing the area and refusing to go back</li> <li>• Behaviour such as flapping or rocking</li> </ul>

Sensory system	Description	Some behaviours that might be observed
Olfactory (smell) or gustatory (taste)	Provides information about different types of tastes or smells	<ul style="list-style-type: none"> <li>Dislike of strong smells or tastes</li> <li>Craving strong smells or tastes</li> <li>Eating non-edible items (sometimes referred to as 'pica')</li> <li>Eating a restricted range of foods</li> </ul>

The way in which sensory challenges impact on daily performance is complex, and individual and sensory deficits may not always result in performance deficits if there have been environmental adaptations or the child has been taught coping strategies. It is most useful if functional assessments of behaviour always include consideration of sensory issues as well as the other core impairments. Occupational therapists and other staff skilled in ASD and sensory issues should provide support and guidance to parents, early childhood education and school staff in assessing and intervening in sensory issues.

### Teaching strategies

Conventional educational environments are associated with a complicated and unpredictable array of sensory experiences. A New Zealand survey of staff associated with early childhood education centres reported that children with auditory processing problems such as ASD were the most severely affected by noise. Under noisy conditions, there was distraction from learning tasks and impaired communication.<sup>248</sup> Children and young people who are challenged by these will need to have adaptations made to their environment and planning to optimise their successful participation.<sup>104 183</sup> Environmental analysis and adaptations and teaching the child or young person coping strategies (such as sensory stories)<sup>249</sup> are therefore the priority interventions in an educational context.

Teachers may need to address some of the following sensory considerations. It is important to note that reactions from children and young people might be either to seek or to avoid the sensations. Often fairly small environmental changes and accommodations for children and young people with ASD can alter significant behaviour challenges by reducing negative sensory reactions. Children usually have some sensory sensitivity which can be helped by adaptations as follows:<sup>250</sup>

- *Acoustics:* Sensitivity to noise in children and young people with ASD can be exacerbated by a lack of sound-dampening measures in areas such as school halls, corridors, technology rooms and science laboratories. Teachers need to consider providing students with a mix of quiet and noisy environments through the school day to provide some relief from the busy environments. In some situations, the child may need to avoid the noisy place or spend very short periods of time there. Other children may be helped by allowing them to wear headphones or ear plugs.
- *Lighting:* for some children and young people with ASD, poor artificial lights or harsh bright sunshine can cause stress and distraction. The position of the child in the classroom and a shady play area might need to be considered.
- *Classroom organisation:* reducing clutter and clearly defining space within the classroom can greatly help students with ASD to access learning. In a regular school setting, the needs of a child or young person with ASD for a structured, low-arousal environment might be accommodated through:



- providing an individual workstation, positioned away from the centre of the classroom
- planning to allow a child or young person to take movement breaks throughout the day
- allowing time for calming sensory activities between activities that are more challenging
- using cues to support the child or young person to shift attention between activities.
- *Playground:* adaptations could include visually marking areas that are safe to access and using stop signs to cue children to stop and wait at exit points to the school.

### 3.2.d Cognitive development and thinking skills

#### Summary of recommendations

Recommendation:	Grade
3.2.4.1 IQ tests should be used with caution: <ul style="list-style-type: none"> <li>• IQ tests, when used, should be accompanied by an assessment of language and an assessment of adaptive functioning in natural settings.</li> <li>• Cognitive assessments should be administered by a psychologist with experience and training in ASD.</li> </ul>	A
3.2.4.2 The cognitive strengths of the child or young person should be used to compensate for areas of difficulty.	C
3.2.4.3 The child or young person's particular interests should be incorporated whenever possible.	C
3.2.4.4 Children and young people should receive carefully planned, systematic instruction tailored to their individual needs and abilities.	B
3.2.4.5 Children and young people should be provided with supports to enhance learning structure.	C

#### Background

##### Cognitive characteristics

The characteristics of ASD are usually described in behavioural terms and there has been considerable effort to understand the cognitive and biological basis for the difficulties children and young people experience in the social, communication and imagination domains.<sup>251</sup>

Various differences in cognition have been noted and a typical developmental sequence of learning new skills cannot be assumed. Difficulties with symbolic representation, imagination, joint attention and preferential orientation to social stimuli are some challenges which appear at an early age.<sup>63 104</sup> Later, difficulties with combining and integrating different kinds of information become more obvious. In formal cognitive testing, abilities which require less verbal mediation (eg, block design) tend to show less impairment.<sup>104</sup> Across time, children may learn to compensate for these difficulties, through teaching or development of their own strategies.<sup>104</sup> However, as in other areas of development, children and young people with ASD



vary greatly in their abilities and approaches to learning and require individualised supports.<sup>226</sup>

About 10% of children with ASD show unusual islets of ability, or ‘splinter’ skills (exceptional skills in a very narrow area). These can either be unusual in relation to the child’s general abilities or (sometimes) in contrast to the skills of typically developing children. They are often related to the child’s particular preoccupations or obsessions, and can sometimes reflect information-processing skills other than just rote-memory skills.<sup>104</sup>

### Types of research

Research focused on understanding the cognitive characteristics of individuals who have ASD is developing rapidly and new papers are published constantly.<sup>63</sup> This work, however, is far from complete, and there is only a partial understanding of the basis of the behaviour of people with ASD.

The research comes from two main areas of endeavour:

- **neuro-biological research**, using new techniques of brain imaging, is providing new insights into the development and working of the brain.<sup>63</sup> These brain studies suggest that there is involvement of broader and more developmentally interrelated systems than would be consistent with a ‘single core deficit’ for ASD. However, clearly some systems are spared, as is demonstrated by normal or even superior functioning in some areas by some individuals<sup>63</sup>
- **psychology** has provided some theories to explain the cognitive characteristics and behaviours of children with ASD and seeks to explore and refine these hypotheses with experimental data.<sup>63</sup>

Neither of these bodies of research currently provides all the answers to the educational questions which arise from the practical issues of teaching and scaffolding the learning of children and young people with ASD. However, the growing body of evidence does provide some directions for educational practice.

### Psychological models

To date, the neuro-biological research and psychological models of ASD have shown only a limited amount of overlap. The dominant psychological theories to explain the core cognitive difficulties in ASD come from three models which suggest:

- core deficits involving **theory of mind** skills
- local rather than central processing, or **weak central coherence**
- difficulties of self-organisation or **executive dysfunction**<sup>63 104 251</sup> (*see also section 1.2.b Young people and adults in Part 1 Diagnosis and initial assessment of ASD*).

#### 1. Theory of mind

The theory of mind hypothesis suggests that individuals with ASD have difficulty identifying and understanding mental states – either their own or others’ – and are thus unable to understand a social world guided by intentions, desires and beliefs.<sup>63 104</sup> It is proposed that these difficulties lead to stilted language interactions, a poor understanding of social situations and little insight into the knowledge and beliefs of other people.<sup>252</sup> A practical limitation with this theory is research that shows teaching theory of mind skills to people with ASD does not necessarily improve real-life social competence, suggesting that the links between theory of mind and sociability are not simple.<sup>63 104</sup>

## 2. Weak central coherence

The theory of weak central coherence suggests that there is a tendency to process all information in a fragmented way with a focus on the details, rather than integrating information into meaningful wholes.<sup>63 104 251 252</sup> This leads to difficulties generalising from one task or situation to the next and difficulties with seeing patterns across experiences. This results in problems in planning ahead and self-organisation. Children with ASD tend not to learn by observing the experiences of other children but often require direct teaching.<sup>252</sup> They also have a tendency to interpret language literally without regard for the context in which it has been expressed.<sup>251</sup>

## 3. Executive dysfunction

The *executive dysfunction* framework looks at the self-organisational elements required to learn, such as attention, inhibition of irrelevant responses, maintenance of a train of thought and use of abstract rules. This theory overlaps the other theories. Executive dysfunction suggests that individuals with ASD have difficulties characterised by poor self-regulation and perseveration, which result in difficulties with change, reduced forward planning and ineffective problem-solving skills (a lack of coordinated reasoning and difficulties adjusting to feedback). There is a general lack of flexibility in thinking.<sup>63 104</sup>

### Limitations and emerging areas of study

As mentioned previously, neuro-biological research suggests that there is involvement with broader interrelated systems which is not consistent with the notion of a 'core deficit' as suggested by each of the psychological theories outlined above.<sup>63</sup>

A theory that is currently re-emerging suggests that a derailment of social motivation is a core deficit. This means that

the young child is not motivated to observe and imitate other people in their environment. This has huge implications for the child's early learning and explains difficulties with joint attention and imitation. This lack of social motivation is seen as the basis for the difficulties described in the above theories.<sup>63</sup>

An emerging area of study, made possible by new techniques, focuses on the cognitive processes used by individuals with ASD rather than just the results obtained. There is early evidence that individuals with ASD may achieve higher than expected results on a given task, but use cognitive processes that contrast markedly from their typical peers. This work has useful future implications for understanding how individuals with ASD think and learn, and consequent lessons about appropriate educational interventions and strategies.<sup>63</sup>

## Implications for professional practice

The way in which cognitive abilities and deficits are interwoven with social and communication difficulties for each child means that no educational intervention can assume a typical sequence of learning. A careful assessment is required of each child and young person's abilities and approaches to learning.

### Assessment

The cognitive ability of children with ASD has been assessed traditionally using IQ tests. The information about IQ in populations of individuals with ASD has changed. Up to 70% were considered to be intellectually disabled, whereas current estimates suggest that fewer than half of children with ASD have non-verbal IQs less than 70.<sup>63 104</sup> This change may be due to more extensive identification of children who are not intellectually disabled and a broader definition of ASD, as well as greater educational opportunities for children.<sup>104</sup> IQ scores have been found to

be relatively stable with older children, but problematic with very young children and those who are more severely impaired.<sup>104</sup>

There is debate about the role of IQ testing for this population.<sup>253</sup> There are difficulties in assessing children with ASD which include:

- the amount of verbal understanding and the verbal responses required
- slower responses, particularly related to auditory processing, which can affect scores on timed tasks
- difficulties related to the child's motivation and subsequent compliance
- difficulties in establishing a ceiling and baseline because the usual test norms may not be appropriate
- difficulties in following standard procedure
- scoring protocols which may be inappropriate.<sup>11</sup>

There are also challenges in interpreting the results. The scatter of abilities which often appears in the profile of children with ASD means that composite scores are misleading.<sup>104</sup>

Children's responses during testing may provide valuable information on their ability to tackle an unfamiliar task. Data on the following may be collected:

- reactions to challenging stimuli
- behaviour and cooperation in structured settings
- memory and attention skills
- motivation
- determination
- perseverative or repetitive behaviour
- resistance to change.

It is important to note that most of these aspects can also be recorded through focused observations of children tackling

tasks in a variety of natural settings and not just in test situations.<sup>11</sup>

### **Suggestions for assessment tools**

IQ tests, if used, should be one of a number of measures and a language assessment should always be included to establish whether some difficulties might be due to difficulties in following instructions<sup>253</sup> (*Recommendation 3.2.4.1*). Test results may also be affected by mood, compliance and motivation. Adaptive behaviour may be a more robust predictor of some areas of development in young children.<sup>104</sup> A parental interview may be an effective way to establish a profile of the young child's strengths and weaknesses. A parental report, however, may overestimate abilities but these can be confirmed with direct observation. Observations should be made in both structured and unstructured settings.<sup>11</sup>

Tests and other cognitive assessments should be administered by a psychologist with experience and training in ASD (*Recommendation 3.2.4.1*). The setting needs to be chosen with particular care<sup>11</sup> and extreme care is required when interpreting test scores, particularly with younger children.<sup>220 253</sup>

IQ tests should not be considered the primary measure of outcome for interventions because there are very complex implications for test selection in this population across ages and developmental levels.<sup>104</sup> When IQ scores are used as outcome measures for interventions, there can be considerable difficulty if the pre-test instrument is no longer appropriate at post-test because of age or other reasons. Different tests produce different results and apparent changes in IQ may be due to test selection rather than real changes.<sup>33 135 258</sup> Also, some apparent changes may reflect an increase in compliance rather than a true change in cognitive ability.<sup>11</sup>

Evaluation of academic skills is very important for planning goals for children who are participating in academic activities.<sup>104</sup>

### Teaching strategies

Children with ASD have diverse and distinctive patterns of development, both as a group and as individuals. An emphasis on thinking skills, concepts, strategies, problem solving and other broad skills will have an effect across all academic areas. The content and sequence need to be decided on the basis of the child or young person's interest and progress.

The following suggestions have been identified to support their learning.

#### 1. Make use of relative strengths

Many children may have relative strengths that can be used in teaching and learning to compensate for the areas in which they have particular difficulty, for example:

- strong visual-spatial skills, which can lead to literacy as a means of communication
- non-verbal problem solving skills, which can be used to structure tasks in a way that motivates a child
- auditory memory which can be a strength that may lead to a child developing socially appropriate phrases for specific situations
- strong visual memory of some students that can be used to teach skills such as spelling<sup>104</sup> (*Recommendation 3.2.4.2*).

#### 2. Make use of children and young people's interests

Children with ASD can often show relatively complex skills and knowledge in an area of their interest, sometimes called 'splinter skills', but show no similar ability in areas that are being taught. Difficulties in social motivation impact enormously on the ability of children with ASD to learn in

areas where they have no interest and, as a consequence, no prior knowledge.

In this context, Steven Shore notes that:

*It is important for teachers to know about their students' interests and build on these existing strengths. Using these topics as the centrepiece of students' academic work helps to keep them focused, engaged and motivated and can also serve as bridges to new topics and skills<sup>254</sup> (p. 298).*

There is evidence that students who are offered preferred activities and objects engage in more self-initiation of questions, use more communication, engage in more social interactions and have enhanced engagement with the task<sup>226</sup> (*Recommendation 3.2.4.3*).

#### 3. Systematic instruction and adequate supports

It is difficult to make recommendations or generalisations about specific practices, and students with significant cognitive and communication difficulties will require greater adaptations, more intensity and greater support. However, student performance, appropriate use of materials, direction following and on-task behaviour can all be improved by maximising material that is within the student's interest, and by:

- incorporating choices
- reinforcing attempts
- pre-task sequencing (giving the child or young person a series of short, easy requests to reinforce expectation and motivation, followed by a more difficult task)
- using the least intrusive prompts first
- using minimal physical prompting
- adequate modelling
- providing natural consequences

- use of peer-tutoring (which can increase instructional time and provide pacing, feedback, error correction, high mastery levels and content coverage)
- using well-planned cooperative learning<sup>220 255</sup> (*Recommendation 3.2.4.4*).

#### 4. Provide structure in the classroom programme

Children and young people with ASD often require much more structure in their environments than others in order to learn.<sup>11 226 254</sup> 'Structure' is not consistently defined, but a programme might be considered structured when the curriculum (activities, schedule and environment) is clear and comprehensible or predictable to both the children or young people and any observers. One suggested test is to observe the student for 10 minutes. If the observer cannot identify the task which the student has been set without further explanation, then further 'structure' is required in the form of visual or other supports (*Recommendation 3.2.4.5*).

Examples of structure include:

- consistent programming
- facilitating transitions, flexibility and change
- schedules of activities
- providing visual supports
- writing instructions on whiteboards
- minimising verbal prompts
- planning and providing choice-making opportunities
- defining specific areas of the classroom and school setting
- allowing some access to repetitive behaviour
- providing behavioural support
- environmental adaptation to plan for sensory needs
- breaking tasks into clear, manageable pieces
- using work baskets to show visually how much work is required and when work is completed
- minimising ambiguity
- planning so that students can finish tasks before moving on
- having adults follow through with expected rewards, consequences and routines and warnings about transitions and changes.<sup>220 226 229</sup>

#### 5. Supports for older children and young people

Preparing the student for what is going to happen offers a number of benefits. When students know what is going to happen, they are better able to think and problem solve, are less anxious and can better attend and comprehend.

Strategies for preparing the student include:

- long-term planning
- including information that will be of interest to the student
- writing step-by-step lists of instructions, for example, within activity schedules and timetables
- providing alternative modes for completing assignments (audio, video, computer, dictation and mind-maps)
- adapting tasks and instructions to the student's level
- pre-teaching important concepts
- encouraging background reading or watching a video on the topic
- providing outlines or copies to follow during whole-class instruction
- specifying expectations for completion (showing students completed models, if necessary)
- using self-management strategies
- cueing systems to get the student back on task (such as secret signals)

- providing mnemonic devices
- priming students about elements that might be of particular interest to them
- highlighting important concepts by:
  - mind-mapping or creating family trees of concepts or ideas
  - making timelines
  - providing graphics and visual organisers
  - providing outlines with topic headings and subheadings<sup>226 229</sup> (*Recommendation 3.2.4.5*).

### 3.2.e Self-management skills and addressing challenging behaviour in education settings

#### Summary of recommendations

Recommendations:	Grade
3.2.5.1 Interventions should start early, as soon as challenging behaviours are of concern, 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
3.2.5.2 Educational interventions should incorporate principles of positive behaviour support, particularly a focus on understanding the function of the child's behaviour ( <i>see Appendix 10.1</i> ).	A
3.2.5.3 Physically aversive procedures should not be used.	A
3.2.5.4 All school staff should understand the goals of a child or young person's behaviour-support plan.	C

Good Practice Point:	
3.2.5.5 Teams in educational settings need access to a quick response in cases of severe behaviour. This may include both specialist medical and behavioural support.	✓

#### Background

##### 'Problem' behaviours

Behaviour problems have been identified as the most challenging and stressful issue facing parents and educators of children and young people with ASD.<sup>104 210</sup> The definition of 'problem behaviour' depends on whether one looks at behaviour from the perspective of a child with ASD or from the perspective of a parent or teacher.

From a child's perspective, parents and teachers demonstrate problem behaviours by putting the child in situations which they find difficult, by:

- making demands they are unable to comprehend
- communicating and expecting communication in ways that are difficult to understand
- expecting them to engage in social interaction and tasks in which they have little or no interest or skill
- limiting engagement in their interests.

From the parent's or teacher's perspective, the child demonstrates problem behaviours by not complying, disrupting classroom activities, having tantrums, destroying property and being aggressive towards themselves or others. Behaviours such as these put children and adolescents at risk of being excluded from social, family, whānau, peer and educational and community activities and therefore need to be understood and addressed.<sup>104</sup>

In addition, there is evidence that for children with ASD, unlike for typically developing children, these behaviours, once established, will persist and worsen rather than decrease with age.<sup>104 256</sup>

### **The focus of interventions**

The nature of behavioural interventions has changed over recent years, from a focus on eliminating behaviours to that of understanding the function of the behaviour for the child or young person and providing an acceptable alternative to serve the same purpose. This may involve modifying environmental triggers and changing consequences of the behaviour as well as change to systems within the organisation. There is no longer an emphasis on deterrence or punishment.<sup>210</sup>

An extensive meta-analysis found that interventions which focused on teaching positive skills to replace challenging behaviours combined with system change had better outcomes than consequence-focused interventions.<sup>257</sup> Many school-wide discipline plans may include the use of consequences such as detentions. Such approaches are unlikely to be effective in teaching more appropriate behaviours to children and young people with ASD. Principals and staff will need to resolve this issue so that all adults support the child's behaviour plan.

There has been a shift from viewing behaviour support as a process by which individuals are changed to fit environments to one in which the environment is recognised as having a role in contributing to the problem behaviour.<sup>104</sup>

There is agreement that interventions are most effective if they begin early, before behaviours become entrenched. The child should not be left to 'grow out of the behaviour'<sup>11 210 256</sup> (*Recommendation 3.2.5.1*).

### **The use of punishment**

Punishment is the use of an aversive procedure in an attempt to eliminate or reduce an unwanted behaviour. Interventions that use punishment-based procedures often have unwanted side effects, such as the child avoiding the punisher and negative feelings for both the child and the adult and seldom result in the replacement of the unwanted behaviour with more desirable behaviours. Many of the more physically intrusive punishment procedures, such as hitting, slapping or spraying with water, are now considered unethical. Physically aversive measures should not be used<sup>104 210</sup> (*Recommendation 3.2.5.3*).



Other forms of punishment such as holding, physical redirection and time-out should only be used when more positive approaches have temporarily broken down. In this circumstance, they should be used as a very temporary measure until a new plan can be developed to support and teach more appropriate behaviours. ‘Time-out’ needs to be used with caution in this population. Many children with ASD enjoy being alone and are not worried about social exclusion. As a result, this intervention may become reinforcing of the negative behaviour if the child sees it as a means of escape from a demanding situation.

Early childhood education centres and schools should have a clear policy statement about the use of restraint, physical redirection and time-out. An individual plan should be developed within this policy for each child at risk. This should outline details of procedures and when they will be used, and be agreed to by the parents/guardians.

### Implications for professional practice

#### Positive behaviour supports

Positive behavioural supports or approaches begin by asking what the child can do instead of what he or she is currently doing (inappropriate behaviour) to receive the same benefit. This shifts the emphasis from simply eliminating the behaviour. This approach allows the child to learn appropriate ways of communicating as well as recognising the rights of the child to have his or her own personal goals. Eliminating behaviours is not only more difficult; it can be detrimental for a child who already has a very limited behavioural repertoire and can mean that the child develops a different problem behaviour to serve the same purpose.<sup>210</sup>

Positive behaviour supports impact on many areas of practice.

#### (a) Preventing or minimising behaviour problems

Research evidence and clinical judgement also agree that providing the child with the skills needed to effectively deal with the physical, academic, communicative, social and sensory aspects of their family, whānau, school, early childhood or community environment is an effective strategy to minimise behaviour difficulties.<sup>102 104 217 256</sup>

Children with ASD who have educational programmes that effectively target appropriate pro-social and positive skills (communication, social interaction, cognitive, adaptive behaviour and sensori-motor skills) are less likely to develop problem behaviours.<sup>11 104</sup> Given that these skills are difficult for this population, many children are at risk of developing alternative ways of coping (often with challenging behaviours) as a response to challenging situations if they do not receive proactive supports and teaching.<sup>256</sup> Increasing engagement in activities, providing choices and using preferred materials and topics are also effective prevention strategies for young children.<sup>217</sup>

Augmentative communication strategies to help with receptive and expressive communication (eg, using visual supports, a word processor with picture communication symbols, work systems and task organisers to help children and young people to understand routines and requirements, as well as instruction in spontaneous expressive communication) are important in helping prevent problems.<sup>11 104 217</sup> It is equally important that these supports are kept up to date and are not removed without careful consideration.



Physical activity and relaxation strategies have been shown to have health benefits and can help prevent behaviour problems, particularly those related to self-stimulatory behaviour<sup>104 183</sup> and disruptive behaviour.<sup>258</sup>

Preparing for and supporting children and young people through transitions, both between activities and different settings, are important to minimise stress and anxiety.<sup>226</sup>

The provision of a quiet space is important for most children and young people with ASD. Regular, timetabled 'down time' can be an important positive strategy to decrease stress and give the child an opportunity to have a break from social expectations and busy environments. Using 'down time' as a reward that is dependent on performance can increase anxiety and should be avoided.

In summary, the key to avoiding and reducing problem behaviours is to provide an appropriate individualised education programme to engage the child or young person<sup>104 217 256</sup> (*for further detail on appropriate programmes see sections 3.2.a; 3.2.b; 3.2.c and 3.2.d*).

#### **(b) Functional assessment of problem behaviours**

Functional assessment is based on the assumption that behaviours are learned and maintained because they serve an adaptive function, resulting in some kind of gain for the participants.<sup>104 256 259</sup>

Functional assessments are usually expected to lead to the identification of the function or purpose of the behaviour for the child or young person. They may also identify environmental elements, ie, the antecedents and consequences which may be supporting the behaviour.<sup>210 217 226 252</sup> An appropriate behaviour plan can then be developed.

It is important to acknowledge the role the core deficits in ASD (communication, socialisation and a lack of flexibility in thought and routines) may play in causing or maintaining behavioural problems.

Many challenging behaviours may have communicative and social functions for the child or be an attempt to control their environment. Once the function of the behaviour has been established, the child may be taught a more appropriate behaviour which has the same 'pay-off', or the environment may be modified to eliminate the 'triggers' for the behaviour.

Some common functions of behaviours are:

- the communication of needs and wants
- social attention
- social avoidance
- escape from difficult or boring tasks or other aversive situations
- access to tangible items and preferred activities
- generation of sensory reinforcement or stimulation.<sup>104</sup>

The steps in a functional assessment are:

- describe the problem behaviour in detail
- identify the times and circumstances (contexts and triggers) that are regularly associated with the occurrence (or non-occurrence) of the behaviour
- identify the consequences that maintain the behaviour
- develop hypotheses regarding the function or purpose of the behaviour and collect observational data to support each hypothesis
- design an intervention, supported by the assessment, to provide an alternative behaviour.<sup>104 256 259</sup>

Effective assessments involve interviews with people in the child's classes or family, as well as direct observation of the behaviour in its usual context.<sup>259</sup> This will provide important information about past patterns of behaviour and skill development. It is also important to consider the possible effects of any co-morbid conditions such as epilepsy.<sup>11</sup> An ecological inventory of the environment may also help identify sensory or human triggers of behaviours. Behaviours maintained by sensory input are more difficult to change.<sup>104</sup> Cognitive and sensory overload, and difficulties switching attention and processing information 'under pressure', are common triggers for individuals to 'shut down', which is often seen as non-compliance.<sup>33</sup>

This assessment and analysis may lead teams to develop hypotheses about causal relationships between environmental changes, skill acquisition and reductions in problem behaviour. This analysis will require input from people who know the child well – particularly parents and teachers – and may help focus attention on what to do before or between bouts of problem behaviour as well as the skills needed by the child.<sup>259 260</sup> For example, if the functional assessment reveals that the inappropriate behaviour serves the purpose of escaping a task, a positive solution could include a reduction in task demand to something manageable by the child as well as teaching functional communication so that the child can signal the need for a break.

Reviews of the research on the outcome of functional behavioural assessments show that they more often result in the choice of positive procedures than punishment procedures, and they are more likely to result in significant reductions in behaviour.<sup>104 256</sup> However, the research warns that in some cases where assessments were conducted, interventions were designed that were not consistent with the actual assessment information.

This highlights the need for education to effectively link assessment and intervention.<sup>256 261</sup>

Research has shown that positive behavioural interventions and support:

- are effective in significantly reducing problem behaviours
- have doubled effectiveness when preceded by a functional behavioural assessment
- were able to be effectively carried out in community settings by the children's parents or usual carers if they are well supported<sup>256</sup> (*Recommendation 3.2.5.2, 6.9, Professional learning and development*).

One study that trained parents to analyse problem behaviours in their young children and teach their children functional communication systems (on the basis of their existing communication skills) increased appropriate social behaviour by 69% and decreased aberrant behaviour by 87%. The intervention took 10 minutes a day and had a high rating for parent acceptability.<sup>104</sup>

#### (c) Teaching positive skills

Comprehensive behaviour plans are intervention strategies which have been developed by the team around the child.

Comprehensive behaviour plans should:

- consider all problem behaviour performed by a child
- be driven by functional assessment outcomes
- be applied across all (or most) of the child's day
- incorporate a number of intervention procedures
- fit the context where they are to be implemented
- emphasise the teaching of positive alternative skills.

### Systems change

The literature on this behavioural support theme is less developed and falls into three categories: generalisation, organisational systems and adult behaviour change.<sup>256</sup>

#### (a) Generalisation

It is no longer considered appropriate to reduce problem behaviour in narrow contexts across narrow periods. Good interventions result in adding elements to the child's life that improve the richness or effectiveness of living and learning. It is therefore very important that all those who will interact with the child (eg, other teachers and relieving or duty teachers) have an understanding of the young person's behaviour-support plan and goals<sup>260</sup> (*Recommendation 3.2.5.4*).

#### (b) Organisational systems

Effective interventions require funding for staff development (*Recommendation 6.10, Professional learning and development*). Staff time and evaluation should be available to support these practices.<sup>104 252 256</sup> There can often be a conflict between school behaviour management policies that have a focus on punishment or negative consequences (eg, detentions) and positive behavioural interventions. These need to be discussed and resolved with the child's team and the whole school staff.

#### (c) Adult behaviour change

Adults may need to change their own behaviour and adapt the learning, physical and social environment to produce durable change in the behaviour of the children. Teachers, families and whānau, and staff may need to be trained to consider elements such as:

- modifying the curriculum
- modifying daily routines, timing of activities and the spaces or places used

- ensuring adequate opportunities for social engagement
- changing communication styles
- following through with planned interventions
- monitoring the effect of interventions<sup>104 210 252 256</sup> (*Recommendation 6.11, Professional learning and development*).

### Environmental change

Behavioural interventions also emphasise environmental adaptations. These include changing the physical characteristics of a setting, altering schedules, modifying curricula and redesigning social groupings as soon as it is suspected these might be problematic for the child.<sup>104 256</sup>

### Other issues

#### Outcome measures

The expected outcomes from positive behavioural interventions and supports are an increase in positive behaviour, decreases in problem behaviour and improvements in quality of life. Possible outcome measures for evaluation include:

- a reduction in the problem behaviour
- child or young person's use of new alternative skills that he or she can now use in place of the problem behaviour
- evidence of new strategies to prevent the future problems in similar risk situations
- report of improvements by families and whānau and others
- increased engagement in positive social interactions with peers and others and greater participation in their school or community setting
- improvements in the child or young person's quality of life (more choice, happiness or satisfaction).<sup>262</sup>

### More serious behaviours

A small number of children and young people with ASD may develop very serious or dangerous behaviours.<sup>102</sup> When this occurs, rapid access to specialist assistance and support and a timely response are essential. This may include both specialist medical and behavioural assistance (*Good Practice Point 3.2.5.5, and see section 4.6: Supporting people with challenging behaviour*).

## 3.3 Particular issues for secondary students

### Summary of recommendations

Recommendations:	Grade
3.3.1 The student should be supported through the multiple transitions of secondary school using schedules and other supports.	C
3.3.2 A careful assessment of the skills which the young person requires for the transition to adult life in the community, leisure activities and the workplace should be undertaken. The outcome should inform the curriculum for the last few years of school.	C

Good Practice Point:	
3.3.3 A quiet place should be provided for the young person to take a break from the busy environment of secondary school.	✓

The bulk of the research around education for children with ASD focuses on the needs of younger children. Strategies for supporting young people at secondary school are often derived from the research around younger children. Further research work needs to be done on the particular issues associated with secondary schools and particularly in meeting the needs of more severely affected young people.

There are particular challenges in providing a suitable programme and meeting the support needs of young people with ASD in the busy environment of a secondary school. Secondary schools require students to respond to many different adults and to be members of many different class groups, each of which may have differing expectations and social

dynamics. This means there is much potential for misunderstanding and inappropriate responses. Young people may have difficulties because of:

- over-selectivity – a tendency to process only one cue or component
- storing irrelevant details
- failing to recognise either the point of the information or which pieces of information are crucial
- secondary teachers' tendency to rely more heavily on verbal explanations, which creates problems even for young people with good verbal skills
- students' difficulties in understanding and communicating their own perceptions and needs

- students' difficulties in understanding the needs of others and ways of meeting them
- lack of motivation
- difficulties because of the emphasis on assessments. Where young people suffer from stress, or have difficulties understanding questions or instructions, they may not demonstrate abilities consistent with the assessment<sup>263</sup> (*Recommendation 6.13, Professional learning and development*).

Students can be helped by being specifically taught problem solving and thinking skills, including:

- explicit teaching in recognising and discarding irrelevant information
- memorising and retrieving information
- collecting ideas
- examining pros and cons
- highlighting key concepts
- checklists
- personalised plans of the school
- devising personal routines
- use of written and visual, rather than verbal information
- increasing structure around exam time.<sup>263</sup>

### Transitions

Secondary schools frequently require students to make many transitions during their day. These include transitions between different teaching areas, teachers, groups of peers and subjects as well as changes of activities within classes. Students will benefit from within-activity schedules as well as daily and weekly timetables to prepare them for these changes. In some cases, tasks may not be

finished within a lesson and this may make the transition from a particular class even more stressful. Some young people may need tasks to be broken into chunks to allow for a sense of completion in each class<sup>229</sup> (*Recommendation 3.3.1*).

It may be particularly important to provide the student with a quiet place to take a break from the busy environment of the secondary school (*Good Practice Point 3.3.3*) (*for further discussion about transitions see section 3.4: Education sector organisation and management*).

### Curriculum for transitioning to adult life and work

The curriculum for students as they near the end of compulsory schooling requires careful planning and thought with input from both family/whānau and school staff. The emphasis should be on critical skills for adult functioning. Assessment of the young person's current skills in the community, work and leisure may help identify priority skills. Observation and information from teachers and family should inform the assessment. The student's preferences for work, leisure and domestic activities should also inform the planning (*Recommendation 3.3.2*).

All students will need goals around communication. For some students, these will emphasise functional communication skills to cope in a wider range of adult community settings. Other students will require attention to pragmatic skills relating to communicating in the work place. It is important that functional academic skills and problem solving are also included. At this stage, however, it is important that there is an emphasis on the young person's particular interests and strengths in developing his/her curriculum<sup>220</sup> (*for further discussion see section 5.1: After secondary school*).

### 3.4 Education sector organisation and management

#### Summary of recommendations

Recommendations:	Grade
3.4.1 All school staff should be offered information about ASD and given opportunities for discussion with an aim towards understanding the needs and experiences of the child or young person.	C
3.4.2 Peers should be provided with information about ASD and given support and encouragement to foster relationships.	C
3.4.3 When making a choice about educational placement, teams should consider whether the following factors are provided or can be created: <ul style="list-style-type: none"> <li>• structure</li> <li>• opportunities for contact with typically developing peers</li> <li>• trained and stable staff</li> <li>• staff with a positive attitude</li> <li>• willingness of all staff and management to work with family/whānau as a team</li> <li>• flexibility to meet changing needs.</li> </ul>	C
3.4.4 Education for students with ASD in New Zealand schools should have the following elements: <ul style="list-style-type: none"> <li>• individualised supports and services</li> <li>• systematic instruction</li> <li>• comprehensible and structured learning environments</li> <li>• specialised curriculum content</li> <li>• a functional approach to problem behaviours</li> <li>• family/whānau involvement.</li> </ul>	B
3.4.5 All transitions for students with ASD should be carefully planned and the child or young person and the new environment carefully prepared.	B

The support of the whole school community is a key factor in the successful education of a child or young person with ASD.

The following key elements were identified as being important general principles.

### Support from management

Teachers and specialist educators who work with children and young people with ASD are involved in difficult work, requiring specialised skills and good judgement. Support for staff from school management has been identified as a critical element of success.<sup>211</sup> Teachers require support from school management for professional learning and development and release for consultation with specialist ASD support staff.<sup>211</sup> School-wide policies need to be reviewed with consideration of the implications for students with special education needs.<sup>104</sup>

There are few specific data on the progress of students with ASD in New Zealand schools. Data need to be recorded about outcomes and difficulties encountered to inform future policy and funding.

### Whole school awareness

The child or young person with ASD benefits both from a consistency of intervention and interactions with staff that have insight into his or her perspective and needs.

Opportunities for the development of whole school awareness and education will result in individual teachers working with school-wide support and encouragement, rather than tackling problems in isolation.<sup>11 104</sup> All members of staff require information, experiences and opportunities for discussion to help them foster more accepting attitudes towards individuals with ASD<sup>211</sup> (*Recommendation 3.4.1*).

### Support for peers

If interactions and relationships with peers are to be successful, the other students require support and information<sup>104 211 263</sup> (*Recommendation 3.4.2*). Units of work and simulations designed to facilitate a better understanding have proved effective.<sup>255</sup> Education of others is important to protect the child from teasing and provide peers with some insight into the child's needs. Other students need to understand the reactions of the child with ASD when he or she is anxious or upset and to be aware of his or her particular interests.<sup>263</sup> Decisions about what others are told about the individual child need to be made with consideration of the views of the family/whānau.<sup>104 209</sup> Staff should be particularly alert for signs of bullying of students with ASD.

### Support for students

There are many students with ASD who do not receive additional support from the Ministry of Education through current special education initiatives. Given the complex nature of this disorder, it is likely that all students will require access to some ASD-specific specialist service at some points in time.

### Support for teachers

The research repeatedly emphasises that there is no one programme, strategy or level of intensity to meet all the needs for all children and that individualised programmes of support are the most appropriate.<sup>104 226</sup>

To understand the needs of students, provide ASD-specific assessments, interventions and strategies and provide effective teaching, teachers require positive attitudes and access to trained and skilled specialist support and coordination (*for further discussion of this point see Part 6, Professional learning and development*).



### 3.4.a Choice of educational placement

Times of transition are stressful for parents and children with ASD. Parents require balanced information about, and support in accessing, the different options and approaches for the next step in the education of their son or daughter.

Decisions need to take account of the needs of the child as well as the preferences of the family/whānau and what options are locally available.<sup>11 255</sup> Options for students with ASD include state funded and integrated primary, intermediate and secondary schools, kura kaupapa Māori, special schools and schools with attached units, private schools and schools of special character. The Correspondence School also provides services for students with special education needs and some families opt for home schooling. However, not all these choices will be available to families in every locality.

*Schooling in New Zealand: A guide states:*

*Special education services are available for children with disabilities, learning or behaviour difficulties who need additional resources to those usually provided in regular education settings. Students with special education needs can receive help in a range of settings, including special schools, special education classes in regular schools and mainstream classrooms. Most students with special education needs attend a regular school.*

*Parents and caregivers of children with special education needs have the same rights as other parents and caregivers to enrol their children at the school of their choice. It is against the law for any educational institution to treat a student differently because of a disability (for example, by denying or restricting services).*

*Where it is the parents' choice, children with disabilities are enrolled with other children in ordinary classes wherever possible. If necessary, buildings are modified, special equipment is provided and extra staff may be appointed to help teachers. As well, advisers may help teachers develop suitable programmes for the individual child.<sup>264</sup>*

The evidence for children with ASD suggests that, in general, the principle of the 'least restrictive environment' should be used and the paramount consideration should be the wellbeing of the child and freedom from persecution, stress and distress.<sup>11 104</sup> Each child should be accommodated in the least restrictive setting required to still meet that student's needs (ie, as close to a regular school setting as possible). A more restrictive environment may be required for students with severe behavioural needs where they represent a danger to themselves or others.

On the whole, the setting is less important than the attitude, level of expertise and understanding about ASD of all those concerned with the child. Where there is expertise and understanding, children make good progress in a variety of settings. Where there is less sensitivity to ASD, children can be adversely affected and may not make good progress academically or socially.<sup>11</sup>

Some research shows that many children and young people make better connections in the natural setting of regular school education, where natural rewards are plentiful and there are good role models.<sup>263</sup> The development of peer-mediated interventions is particularly helpful.<sup>104 211</sup>

For regular education placements to be successful, educators require knowledge of and access to empirically validated strategies and professional supports.<sup>255</sup> Settings need to provide sufficient structure to support the child or young person.<sup>11 104</sup>



It is important that placement decisions be flexible and not irrevocable, as the child's needs change over time.

In conclusion, the most suitable setting will be one:

- that provides adequate structure and gives the child or young person opportunities for contact with typically developing peers
- where staff are well trained and have a positive attitude, expertise, understanding and a willingness to work in a team with the family/whānau
- that has the ability to be flexible in meeting the child's needs over time (*Recommendation 3.4.3*).

### 3.4.b Implications for the New Zealand school sector

The literature for early childhood includes variable age ranges, with some studies covering up to the age of seven years.<sup>11 104</sup> The literature suggests that it is appropriate that programmes for young children are adapted and continue through their first years of transition to compulsory education. Researchers identified six core elements of effective educational practices for school-aged children and young people:

- Individualised supports and services  
This element includes incorporating a focus on the child/young person's strengths and weaknesses, as well as family/whānau preferences, child and young person preferences and interests to determine the most appropriate intensity and level of instruction to meet the child or young person's individual goals.
- Systematic instruction  
This involves carefully planning for instruction by identifying valid educational goals, carefully outlining instructional procedures for teaching,

implementing the procedures, evaluating their effectiveness and adjusting the instruction on the basis of the evaluations.

- Comprehensible and structured learning environments  
This includes strategies such as organising the instructional setting, providing a schedule of activities that is kept up to date, carefully planning and providing choice-making opportunities, providing preventive behavioural support and providing supports to assist with transitions, flexibility and change.
- Specific curriculum content  
This component describes prioritising the core difficulties for individuals with ASD in the areas of communication and social interaction, and the skills that are required to participate.
- Functional approach to problem behaviour  
This describes the process by which the child/young person's problem behaviour is not merely decreased or eliminated, but is replaced with an appropriate alternative or replacement behaviour that results in the same or similar consequences (*this is described in detail in section 3.2.e*).
- Family involvement  
Families/whānau should be provided with the information they require to be involved in making decisions for their child/young person and to participate as part of the team designing the child or young person's programme<sup>226</sup> (*Recommendation 3.4.4*).

These points, on the core elements of effective teaching of children and young people with ASD, are further expanded in Appendix 7.

### Collaborative teams in education

Developing and maintaining effective collaborative relationships are important components in special education support.<sup>104</sup> Most teams will consist of core members who will generally include the student's classroom teacher, special education needs coordinator (SENCO) and the student's family and whānau. Wider teams will include other staff such as psychologists, speech-language or occupational therapists and other teachers, paraprofessionals and school staff.

Teams need a dual focus in delivering supports to students by directing attention to the student and also to the team itself. Student-centred efforts include:

- developing the student's schedule or programme collaboratively
- designing accommodations and adaptations together
- finding ways to ensure consistency and quality among school staff
- shared problem solving about specific issues
- co-teaching and co-working
- planning for successful transitions within, between and beyond early childhood education settings and schools.

Team-centred efforts include:

- understanding other team members' roles and skills
- clarifying the team's values
- learning to communicate effectively among team members
- identifying and resolving concerns
- reaching consensus on decisions
- developing trust and respect.<sup>265</sup>

The biggest barriers to collaborative teaming are negative staff attitudes and a lack of time. However, there is good evidence that collaborative teams enhance teacher satisfaction with their jobs, improve communication and collaboration skills for all participants and result in better decisions and results for students.<sup>265</sup>

### The roles of specific professionals

The education section of the ASD Guideline has deliberately not closely defined specific roles for particular professional groups such as occupational therapists and speech-language therapists when working in early intervention and educational settings. The intention was to identify the knowledge and skills which are required to support children and young people with ASD in a variety of settings.

Members of a well-functioning collaborative team will share information and enskill one another. It is expected that each professional will take the lead in areas where they have particular expertise, for example, speech-language therapists in planning communication strategies. The skills of different professionals will overlap in some areas. Some teams may have gaps in the skills and knowledge available to them from actual members of a child/young person's team. In such circumstances, professionals may need to act as consultants to the team from a distance.

Readers who seek more details about the work of various professional groups should source information from the relevant professional bodies. These include:

- New Zealand Association of Occupational Therapists (NZAOT)
- New Zealand Speech and Language Therapists Association (NZSTA)
- New Zealand Psychological Society.

### 3.4.c Supporting and planning for transitions

Times of transition (from one teacher to another, as well as from one setting to another) are stressful for all children and young people and their parents.

Times of transition provide additional challenges for students with ASD. These can include transitions from home to school, between activities, from place to place, between classrooms and from one school to another. Strategies to help students to understand the purpose and expectations of transitions are essential and include:

- visual supports
- maps
- priming
- schedules of events
- planning for changes and sharing plans with the child
- social stories
- careful analysis of difficulties (not always what is assumed).<sup>209 219</sup>

Developing and regularly updating a personal profile for students is one way to ensure recognition of their skills and behaviours, as well as their preferences, interests, effective strategies and prior learning (*Recommendation 3.4.5. For further discussion of transitions see sections 3.1 and 3.3*).



## Part 4

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### Treatment and management of ASD

“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.”

## Part 4 Treatment and management of ASD

This section covers the management of behavioural, emotional and mental health difficulties that can be experienced by children, young people and adults with ASD. Many of these difficulties can be prevented, minimised or alleviated by interventions with a totally educational component (*see Part 3: Education for learners with ASD*). This section applies to interventions with a different focus for these problems.

## 4.1 Introduction

### Summary of recommendations

Recommendations:		Grade
4.1.1	Treatment should encourage functional development, teach skills for independent living, and minimise stress for the person with ASD, and their family and whānau.	B
4.1.2	Treatments of ASD and co-morbid conditions should be matched to the specific characteristics and needs of the person concerned.	B
4.1.3	Treatments of ASD and co-morbid conditions should be based on comprehensive diagnostic and ongoing assessments.	B
4.1.4	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
4.1.4a	Gastrointestinal problems, specifically constipation, chronic diarrhoea, altered bowel habits, and encopresis (faecal soiling), are more common in children and young people with ASD compared with typically developing peers. ( <i>see Appendix 10.4</i> ).	B
4.1.4b	Children and young people with ASD should have a full evaluation that includes a thorough assessment of gastrointestinal function. Some children, particularly those with social communication difficulties, may have atypical presentations such as increased anxiety, irritability, disordered sleep patterns, and unusual vocalisations and movements. ( <i>see Appendix 10.4</i> ).	C
4.1.5	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

Autism spectrum disorders are behaviourally defined. Working through the symptoms of ASD, it is clear that behavioural and emotional problems typify the disorder, and that long-term problems may arise if the communicative, social and ritualistic/obsessive aspects of ASD are not attended to.<sup>256 266 267</sup> Common behavioural problems include hyperactivity, attention difficulties, repetitive and ritualistic behaviours, self-injury, tics, and unusually strong interests.<sup>42 268</sup> Problems with mood are common,<sup>42</sup> as are social difficulties.<sup>269</sup> Not surprisingly, parents of children and young people with ASD frequently seek behavioural advice, as do families and carers of those adults with ASD who also have an intellectual disability. Good treatment of ASD encourages normal development and skills for independent living, while minimising the stress of the person with ASD and their family/whānau, and treatments are likely to be more successful if they are targeted on specific skills development (*Recommendation 4.1.1*).

There is a growing literature on the mental health concerns of people with ASD. Emotional problems, such as poor anger and anxiety control and depression, appear to be common experiences of young people and adults with ASD,<sup>269 270</sup> especially at times of transition and at adolescence. Major psychiatric disorders (eg, bipolar affective disorder, psychoses, schizophrenia and catatonia) have also been described in research and academic case studies.<sup>26 54 270–275</sup> A study of the diagnostic accuracy of the Autism Spectrum Disorder Screening Adults Questionnaire found that 1.4% of the psychiatric population screened (n=1323) had ASD, most previously undiagnosed.<sup>74</sup> The increased prevalence of psychiatric problems in the population of people with intellectual disabilities has been well established in the literature.<sup>167</sup> Preliminary research on the prevalence of psychiatric symptomatology in people with intellectual disabilities with and without ASD suggests that those with ASD have a much higher chance of developing psychiatric problems.<sup>268</sup>

There is debate about whether the behavioural, emotional and mental health issues of people with ASD should be considered co-morbid disorders (ie, completely separate disorders that occur at the same time as ASD) or underlying symptoms of ASD itself.<sup>270 271</sup> Nevertheless, international guidelines for children with ASD suggest that treatments of ASD itself should be distinguished from treatments of co-morbid disorders<sup>11</sup> and treatment should be individualised (*Recommendation 4.1.2*). While no treatment or medication actually cures ASD, such interventions can sometimes effectively manage associated emotional and mental health problems.<sup>273</sup>

The first step in the treatment of the behavioural, emotional and mental health problems of people with ASD is comprehensive assessment<sup>42</sup> and assessment should be ongoing (*Recommendation 4.1.3*). Initial diagnostic assessment has been covered elsewhere in this guideline (see *Part 1 Diagnosis and initial assessment of ASD*). Pre-treatment assessments gather information on behavioural, emotional and mental health difficulties in much more detail, address differential diagnosis, and screen for medical conditions before developing psychological programmes<sup>256 266</sup> (*Recommendation 4.1.4*). Note that research on gastrointestinal issues in children and young people with ASD (*Recommendation 4.1.4a, 4.1.4b*) was comprehensively updated as part of the living guideline process, and is summarised in Appendix 10.4, and available as full text from the Ministry of Health website.<sup>15</sup>

Treatments of ASD and co-morbid conditions are most appropriate when derived from comprehensive diagnostic and ongoing assessments, given that no one option works for all people with ASD.<sup>42 256 270</sup> Components of comprehensive treatment plans include those that address behavioural needs, educational interventions, psychosocial treatments, communication and the suitability (or not) of medication<sup>42</sup> (*Recommendation 4.1.5*). In many cases, education on ASD and post-diagnosis counselling may help ameliorate various issues. However, often the behavioural, emotional and mental health needs of people with ASD will need to be specifically addressed.



## 4.2 Problem minimisation and avoidance

### Summary of recommendations

Recommendations:		Grade
4.2.1	The development of social skills and community support groups for young people and adults should be undertaken to minimise and avoid problems.	C
4.2.1a	Facilitated and structured social skills groups should be considered for high functioning children and young people with ASD ( <i>see Appendix 10.6</i> ).	B
4.2.2	Parents, families and whānau should be provided with information on interventions and supports that are available locally, nationally and internationally.	C

Good Practice Points:		
4.2.1b	Social skills groups approaches in New Zealand need to be responsive to the cultural and linguistic diversity of the group participants ( <i>see Appendix 10.6</i> ).	✓
4.2.1c	Decisions about participating in social skills groups should be guided by whether a person with ASD values it, and whether they are expected to benefit from it ( <i>see Appendix 10.6</i> ).	✓
4.2.3	Routine monitoring (or monitoring schemes) of young people and adults should be considered to minimise and avoid problems.	✓
4.2.4	Attention to the core deficits of ASD as experienced by young people and adults should be considered to minimise and avoid problems.	✓

Because of their social and communication problems, 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. Not intervening and hoping the child will outgrow behavioural problems is a mistake.<sup>256 270</sup> Many of the emotional, behavioural and even legal problems experienced by young people and adults with ASD arise from communication difficulties, social misunderstanding, obsessions, compulsions, and ritualistic or repetitive behaviours,<sup>266</sup> which are frequently evident in childhood. Therefore problem minimisation and avoidance early in life is essential (*see section 3.2.e: Self-management skills and addressing challenging behaviour in education settings*).

Given individual and family differences, no one method or style of intervention is likely to be effective for all children with ASD and intervention will need to be adapted to individual needs.<sup>266</sup> Accordingly, parents, families and whānau of young children with ASD should be supported to:

- learn about ASD as it affects their child, and adapt the home environment and routines accordingly
- develop routines within the home that work for both the child and the family and whānau
- ensure that behaviours that are ‘cute’ in young children do not develop into problem behaviours for people of an older age
- develop methods of communication that can be used inside and outside the home
- give their child opportunities to mix with other children, learn social skills, and develop friendships
- seek referrals for specialist services (eg, speech and communication therapy, behaviour support, occupational therapy, clinical psychology) if they need assistance to help their child develop skills or to prevent or manage problem behaviour.<sup>256 270 276–278</sup>

Problem minimisation and avoidance is equally as important for services and paid staff. Agencies providing services for people with ASD of any age (including adulthood) can implement strategies designed both to avoid the development of problem behaviour, and to intervene early, such as ensuring that members of staff have good education in ASD, that education is current and that agency procedures incorporate best practice in ASD (*Recommendation 6.17, Professional learning and development*).

Adequate service provision for young people and adults with ASD and routine monitoring may reduce the number and severity of stressors experienced by people with ASD and, in doing so, minimise and avoid problems (*Good Practice Point 4.2.3*). Attention to educational, work and vocational options (*see section 5.1 After secondary school*) could address some of the problems associated with financial hardship, social isolation, boredom, and lack of a valued role in society. Addressing the communication needs and social skills of a person with ASD, which are core deficits of this condition, is frequently effective in preventing and/or managing behavioural and emotional problems (*Good Practice Point 4.2.4*). Promising outcomes have been described for adults with ASD following participation in relatively inexpensive and time-efficient social skills groups<sup>279</sup> and community support schemes<sup>9 283 284</sup> (*Recommendation 4.2.1*). Research on social skills groups for young people and adults) was comprehensively updated as part of the living guideline process, and is summarised in Appendix 10.6, and available as full text from the Ministry of Health website<sup>17</sup> (*Recommendation 4.2.1a, Good Practice Points 4.2.1b and 4.2.1c*).

For all people with ASD and their parents, family and whānau, information on interventions and supports that are available locally is of utmost importance. As well as formal services provided by the Ministries of Health and Education, people may value contact with people in a similar situation to themselves. Contact by telephone, the Internet, informal support groups and joining ASD and/or disability associations should be encouraged (*Recommendation 4.2.2. See Part 2: Support for individuals, families and carers*). However, because of the current state of scientific knowledge, caution should be exercised when selecting interventions (*see sections 4.3, 4.4 and 4.5*).

### 4.3 Psychological approaches to the management of ASD

#### Summary of recommendations

Recommendations:		Grade
4.3.1	Professionals should, objectively and honestly, interpret research evidence for parents or people with ASD.	C
4.3.2	Structured educational/daily living programmes and interventions with an emphasis on visually based cues should be implemented. They should focus on skill enhancement and establishment of communication strategies. Family-centred treatment approaches should be provided.	C
4.3.3	Professionals, people with ASD, family, whānau and carers should evaluate treatment approaches before and during implementation.	C
4.3.4	Behaviour management techniques should be used to intervene with problem behaviours following functional behaviour assessment ( <i>see Appendix 10.1</i> ).	A
4.3.5	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
4.3.5a	Interventions and strategies based on applied behaviour analysis (ABA) principles should be considered for all children with ASD ( <i>see Appendix 10.1</i> ).	A
4.3.5b	Early intensive behavioural intervention (EIBI) should be considered as a treatment of value for young children with ASD to improve outcomes such as cognitive ability, language skills, and adaptive behaviour ( <i>see Appendix 10.1</i> ).	B
4.3.6	Consumers of applied behaviour analysis interventions should refer to recently published guidelines for identifying, selecting and evaluating behaviour analyst services for people with ASD ( <i>see Appendix 10.1</i> ).	C
4.3.7	The feasibility of establishing publicly funded, ASD-specific behavioural services should be investigated.	C
4.3.8	Insight-oriented therapy and psychodynamic therapy are not recommended as suitable treatments for people with ASD.	C
4.3.9	Cognitive behaviour therapy should be considered as a suitable treatment for many behavioural, emotional and mental health difficulties.	C
4.3.9a	Broadly defined cognitive behaviour therapy, adapted for ASD, may assist adults with mental health conditions ( <i>see Appendix 10.7</i> ).	C
4.3.10	Cognitive behaviour therapists should adapt their techniques to take into account the characteristics of people with ASD.	C

Good Practice Points:		
4.3.9b	Cognitive behaviour therapy (CBT) has been designed and evaluated predominantly for people without ASD. More research is recommended to further develop and evaluate effective cognitive behaviour therapies and their necessary adaptations for people on the spectrum as well as appropriate and valid outcome measures for research in this field. As it seems likely that some individuals receiving CBT benefit and some do not, future research should also investigate what personal characteristics and aspects of therapy best predict treatment effectiveness (see <i>Appendix 10.7</i> ).	✓
4.3.10a	<p>The following adaptations to cognitive behaviour therapy are recommended:</p> <ul style="list-style-type: none"><li>• <b>Use a structured approach</b> and minimise anxiety about the therapeutic process by being <b>explicit</b> about roles, times, goals and techniques.</li><li>• Extend the <b>number of sessions</b> and <b>time provided</b> to conduct tasks to accommodate slower information-processing and the mental demands of the therapeutic process. Be <b>flexible</b> about the length of each session and offer breaks to allow for cognitive and motivational deficits.</li><li>• Provide <b>psycho-education</b> about autism, emotions, and mental health challenges relevant to the client.</li><li>• Concentrate on <b>well defined</b> and <b>specific difficulties</b> as the starting point for intervention, with less emphasis on changing client's cognitions.</li><li>• Be more <b>active</b> and <b>directive</b> in therapy, where appropriate, including giving suggestions, information, and immediate and specific feedback on performance. Examine the rationale and evidence for inaccurate, automatic thoughts and collaboratively develop alternative interpretations, concrete strategies and courses of action.</li><li>• Teach <b>explicit rules</b> and their appropriate context, including the use of verbal, nonverbal and paralinguistic cues to a social situation.</li><li>• Incorporate specific <b>behavioural techniques</b> where appropriate, such as relaxation strategies, meditation, mindfulness, thought stopping or systematic desensitisation.</li><li>• <b>Communicate visually</b> (eg, using worksheets, images, diagrams, 'tool boxes', comic strip conversations, video-taped vignettes, peer-modelling, and working together on a computer).</li><li>• <b>Avoid ambiguity</b> through minimising the use of colloquialisms, abstract concepts and metaphor. Use specific and concrete analogies relatable to the client's concerns.</li></ul>	✓

Good Practice Points:		
	<ul style="list-style-type: none"> <li>• Incorporate <b>participants' interests</b> in terms of content and modes of content delivery to enhance engagement.</li> <li>• Involve a <b>support person</b>, such as a family member, partner, carer or key worker (if the person with autism agrees) as a co-therapist to improve generalisation of skills learned within sessions (<i>see Appendix 10.7</i>).</li> </ul>	✓
4.3.11	Applied behaviour analysis (ABA) interventions and strategies should be relevant to the child's context and culture ( <i>see Appendix 10.1</i> ).	✓
4.3.12	Interventions based on the principles of ABA can be introduced before the diagnosis of ASD is confirmed in a child displaying some of the symptoms of ASD ( <i>see Appendix 10.1</i> ).	✓

There are many approaches to treating and managing ASD. Interventions and approaches that make compelling claims to cure ASD are easily sourced through the Internet, although many make claims that have not been substantiated.<sup>212 266 280 286–291</sup> Although claims are often strongly worded, a great deal of the information that is readily accessible is biased, and claims that certain interventions 'cure' ASD or lead to 'recovery' have been described as misleading and irresponsible.<sup>281</sup>

While every parent or person with ASD has the right to seek treatment from any source they believe may work for them, professionals have a responsibility to interpret research evidence for them and be as objective and honest as possible (*Recommendation 4.3.1*). The absence of appropriately supportive data for most of the treatment approaches underlies the reluctance that many authorities worldwide share for publicly funding specific treatment methods.<sup>212 282 283</sup> Furthermore non-established treatments can be costly in time and money and some have adverse effects.<sup>284</sup>

As ASD represents a heterogeneous spectrum of disorders, treatments may have differential effects in individuals, making the identification of effective treatments difficult. There is a great deal of

variability in response to treatment and some individuals may show apparently spontaneous improvement in symptoms in a particular area for unidentified reasons. In such a situation, if an intervention has been recently implemented, the improvement can be erroneously attributed to the treatment, even when the treatment is actually ineffective.

The following intervention guidance has been suggested (which is also contained in Part 3: Education for learners with ASD – the same principles apply in both settings):<sup>285</sup>

- treatment programmes should be individually designed, taking into account the individual's cognitive level, severity of autistic symptomatology, overall developmental level, chronological age and temperament/personality (*Recommendation 4.1.2*)
- structured educational/daily living programmes should be considered; programmes with an emphasis on visually based cues can provide a predictable and readily understandable environment, minimising confusion and distress to the person with ASD (*Recommendation 4.3.2*)

- interventions should take account of the core deficits of autism (eg, communication, social skills and stereotyped and ritualistic behaviour) (*Good Practice Point 4.2.5*)
- many undesirable or challenging behaviours reflect limited behavioural repertoires or poor communication skills, so focus on skill enhancement and establishment of more effective communication strategies are often the most successful means of reducing difficult or disruptive behaviours (*Recommendation 4.3.2*)
- family-centred treatment approaches result in greater generalisation and maintenance of skills. Development of management strategies that can be implemented consistently but do not demand extensive sacrifice in terms of time, money or other aspects of family life seem most likely to offer benefits for all involved (*Recommendation 4.3.2*).

Guidelines for evaluating treatment options for people with ASD advise parents, family, whānau and professionals to:

- ask specific questions about the treatment regarding its goals, components, style, target group, outcomes, efficacy, effectiveness (and the best method for evaluating this), negative effects, risks and safeguards
- find out about therapist experience, qualifications and professional association
- be hopeful, but conservative, about any new treatment where the efficacy of the treatment has not been proven
- remember that the primary goal of any treatment should be to help the person with ASD live as full a life as possible within society
- beware of any programme that claims to be effective for all people with ASD
- be cautious of programmes that do not allow individualisation

- recognise that there are likely to be several suitable treatment options for each person with ASD
- recognise that treatment choices should be based on the results of the person's individual assessment
- avoid treatment approaches that do not provide information on how to assess whether the person with ASD is suitable for that treatment
- use appropriate methods to determine whether the treatment was effective (eg, appropriate behavioural data; trialling the treatment for a sufficient length of time, completion of appropriate questionnaires about the targeted behaviours/skills before and after treatment, telling no one when a treatment has started, and monitoring of the behaviour of the person with ASD by making written notes)<sup>286–289</sup> (*Recommendation 4.3.3*).

#### 4.3.a Behavioural interventions

Behavioural interventions, following careful and thorough functional behaviour assessment, are often the most appropriate means of addressing behavioural problems for people with ASD<sup>42 256 266 270 277 278</sup> and those with an intellectual disability<sup>257 290</sup> (*Recommendation 4.3.4*). However, assessment must be comprehensive and consider all potential causes of behavioural problems (eg, pain, undiagnosed medical issues, sensory problems, abuse, etc).

Although differences of opinion exist regarding how behavioural interventions are described (eg, applied behaviour analysis, positive behaviour support, behaviour modification, behavioural programming, etc),<sup>256 291</sup> and various methods of behavioural assessment and interventions development have been published, all behavioural interventions are based on the science of applied behaviour analysis. It is beyond the scope of the New Zealand ASD Guideline to provide details

on how a practitioner should conduct a behavioural assessment, and how behavioural interventions are developed and implemented. A large literature on this exists, and includes many lengthy texts. Features common to behavioural interventions of good quality are:

- person-centred planning: through which the person with ASD remains the focus of the assessment and treatment, and the individual characteristics are taken into account
- functional assessment: a comprehensive assessment, through which all the factors that reliably precede, predict and maintain the problem behaviour (including setting, specific triggers, reinforcers) are identified, through means of thorough interview, observation, recording and/or formal testing
- positive intervention strategies: a preference for interventions which use positive reinforcement, as opposed to punishment
- multifaceted interventions: packages of treatment which include more than one intervention, such as specific intervention procedures combined with staff and carer education
- focus on environment: designing or altering the environment of the person with ASD to effect behaviour change
- meaningful outcomes: measures of successful intervention which are significant to the person with ASD and/or the people with whom they associate
- focus on ecological validity: interventions which are settings-specific and are implemented in the places that people live, study, work, socialise or otherwise spend their time, so that they can be transferred or generalised to other settings
- systems-level intervention: interventions that take into account the systems-level issues and overall context (eg, agency policy, staff professional learning and development, financial constraints, team values etc) and, when required, seek to alter matters at the systems level<sup>291</sup> (*Recommendation 4.3.5*).

Note that research on applied behaviour analysis (ABA) and early intensive behavioural intervention (EIBI) in children with ASD was comprehensively updated as part of the living guideline process, and is summarised in Appendix 10.1, and available as full text from the Ministry of Health website<sup>12</sup> (*Recommendations 4.3.5a and 4.3.5b, and Good Practice Points 4.3.11 and 4.3.12*).

Within New Zealand, a range of professionals develop and implement behavioural interventions. However, there are significant variations in educational level, professional affiliation or accreditation, expertise and supervision arrangements, all of which can impact on intervention quality. Consumers are advised to scrutinise the expertise of professionals providing behavioural interventions, including checking that the person has the appropriate professional affiliation (eg, for those claiming to be psychologists, teachers, applied behaviour analysts, etc) (*Recommendation 6.14, Professional learning and development*). For example, it is against the law (Health Practitioners Competence Assurance Act) for a person to call him/herself a psychologist if he/she is not registered with the Psychologists Board. There is growing international pressure for practitioners of applied behaviour analysis to be formally accredited, as a means of ensuring service quality and good professional practice<sup>292</sup> (*Recommendation 4.3.6*), but so far there are few accredited applied behaviour analysts in New Zealand. For further information, interested parties are referred to recently published guidelines



for identifying, selecting, and evaluating behaviour analysts for people with ASD.<sup>292</sup>

Currently there are no publicly funded, ASD-specific, behavioural services in New Zealand<sup>292</sup> (*Recommendation 4.3.7*).

#### 4.3.b Cognitive behaviour therapy

Often the first source of formal assistance when people experience emotional or behavioural difficulties is a counsellor. Although some counsellors may have good skills in working with people with ASD, many do not. Lack of understanding of ASD and approaches that work effectively with ASD are problems shared by many counsellors, therapists and other mental health professionals working with adults.<sup>47 293 294</sup> Knowledge and understanding of ASD are crucial for the success of any therapeutic encounter. Given the importance and financial cost of counselling, a counsellor or therapist must be carefully selected.

Of equal importance is the theoretical orientation of the counsellor or psychologist. Because of the social and communicative aspects of ASD, expert opinion suggests that psychodynamic styles based on insight, introspection and the development of a therapeutic alliance are unlikely to be successful.<sup>270 295</sup> (*Recommendation 4.3.8*). Cognitive behaviour therapy (CBT), a therapeutic approach well supported across problem types and many different populations (including the intellectually disabled), may be more promising.<sup>46 270 289 296 305</sup> (*Recommendation 4.3.9*). The more structured format of CBT and practical emphasis on the here-and-now may account for this.<sup>295 297 298</sup> CBT is derived from applied behaviour analysis and behaviour therapy, and addresses the role of beliefs about events in the development and maintenance of emotional distress. CBT typically consists of five components:

- psycho-education about the emotional and/or mental health difficulty, and education about CBT itself
- teaching the person how to control the physical symptoms of the problem (eg, relaxation training, specific breathing techniques)
- teaching the person how to identify faulty/irrational cognitions (thoughts), and how to change the cognitions into a more appropriate/helpful form (cognitive restructuring)
- assisting the person to practice his/her new coping skills in situations where the problematic emotions/behaviours occur; this may be a graduated process
- developing long-term plans (relapse prevention plans) aimed at helping the person to identify and respond appropriately to early warning signs and triggers.<sup>296</sup>

Because of the symptoms of ASD, even experienced cognitive behaviour therapists working with people with ASD need to understand ASD and how the characteristics of the disorder are likely to present in therapy. Advice to cognitive behaviour therapists on adapting their techniques to more appropriately suit people with ASD includes:

- concentrate on well defined and specific difficulties
- attend to and intervene with the core deficits of ASD (communication, social skills, stereotypical and repetitive behaviour) and alter techniques accordingly
- minimise anxiety about the therapeutic process by being explicit about roles, times, goals and using techniques like repertory grid
- be flexible about the length of sessions and leaving the treatment room



- avoid direct challenges to personal beliefs, as these may be misinterpreted as a personal attack; instead, examine the rationale and evidence and collaboratively develop alternative interpretations and beliefs
- use visual imagery
- encourage clients to write down positive things, rather than relying on changing thoughts in their heads
- incorporate specific behavioural techniques where appropriate, such as relaxation strategies, thought stopping or systematic desensitisation<sup>267 295 297 299</sup> (*Recommendation 4.3.10*).

Research on cognitive behaviour therapy for adults was comprehensively updated as part of the living guideline process. It is summarised in Appendix 10.7, and is available as full text from the Ministry of Health website.<sup>18</sup> (*Also see new recommendation 4.3.9a, and new good practice points 4.3.9b and 4.3.10a.*)

## 4.4 Pharmacological interventions

### Summary of recommendations

Recommendations:		Grade
4.4.1	SSRIs (eg, fluoxetine) may be effective for some children with ASD and high anxiety and/or obsessive symptoms. However, in the absence of good evidence, these drugs should be used with caution and careful monitoring.	B
4.4.1a	Citalopram cannot currently be recommended for the treatment of repetitive behaviours in children and young people with ASD ( <i>see Appendix 10.2</i> ).	B
4.4.1b	Citalopram's use for established comorbid indications for children and young people (eg, anxiety, obsessive compulsive disorder) should be considered with significant caution on a case-by-case basis, after full disclosure of side effects to the individual and their family and careful ongoing monitoring ( <i>see Appendix 10.2</i> ).	C
4.4.2	There is insufficient evidence to make any recommendation in relation to the use of other types of antidepressants in children with ASD.	I
4.4.3	Risperidone is effective in reducing aggressive behaviour, irritability and self-injurious behaviour in children with ASD. It may be useful in improving restricted interests and patterns of behaviour. 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. Risperidone is currently on the IMMP (Intensive Medicines Monitoring Programme) in New Zealand and all new clinical events should be reported.	B

Recommendations:	Grade
<p>4.4.4 In most circumstances risperidone should be the first medication used when indicated for significant irritability in children and young people with ASD. Aripiprazole could be used as a second-line treatment where individuals have demonstrated poor efficacy to risperidone or where there is concern regarding significant metabolic or adverse effects. Clinicians prescribing these drugs need to keep up to date with current literature (<i>see Appendix 10.2</i>).</p>	B
<p>4.4.5 Typical antipsychotics are effective in reducing motor stereotypies, temper tantrums and improving social relatedness. These drugs have a high rate of adverse effects and are therefore not recommended for first-line use. Haloperidol, in particular has been shown to cause little weight gain. Thioridazine should only be used in exceptional circumstances, as recent reports have implicated thioridazine in cases of sudden death.</p>	B
<p>4.4.6 Methylphenidate is effective for some children with ASD and co-morbid ADHD. It should be used with caution because of the high risk of adverse effects.</p>	C
<p>4.4.7 Melatonin can be recommended for use in children and young people with ASD who are experiencing significant sleep problems (<i>see Appendix 10.2</i>).</p>	B
<p>4.4.7a Benefits and adverse effects of longer term treatment of melatonin require further investigation (<i>see Appendix 10.2</i>).</p>	C
<p>4.4.7b Behavioural strategies (eg, sleep hygiene) should always be used in conjunction with melatonin (<i>see Appendix 10.2</i>).</p>	C
<p>4.4.8 Co-morbid bipolar disorder should be managed in consultation with an appropriately experienced psychiatrist.</p>	C
<p>4.4.9 Children with ASD who also have epilepsy should be managed in consultation with an appropriately experienced clinician.</p>	C
<p>4.4.10 There is insufficient evidence to make any recommendation with respect to the use of the following drugs for ASD-specific symptoms in children with ASD. However, these medications are in current use, and may be used by experienced clinicians, who maintain up to date knowledge of the literature:</p> <ul style="list-style-type: none"> <li>• clonidine</li> <li>• sedatives (benzodiazepines, antihistamines).</li> </ul>	I
<p>4.4.11 There is insufficient evidence to make any recommendation with respect to the use of the following drugs for ASD-specific symptoms in children with ASD. The opinion of the Guideline Development Team is that these medications are unlikely to be useful:</p> <ul style="list-style-type: none"> <li>• amantadine</li> <li>• intravenous immunoglobulins</li> <li>• naltrexone.</li> </ul>	I

Recommendations:	Grade
4.4.12 The use of the following drugs and agents is NOT recommended: <ul style="list-style-type: none"> <li>• fenfluramine</li> <li>• secretin</li> <li>• chelation therapy.</li> </ul>	A A C
4.4.13 Clinicians prescribing more than one medication or prescribing any additional medication must consider the possibility of drug interactions.	C

### Children and young people

The mainstays of treatment for behavioural, emotional and mental health problems are supportive, educational and behavioural approaches. No medication has been identified as a cure for ASD. However, a number of medications may be helpful in significantly improving various target symptoms and associated conditions. Many of these same medications can continue to be used in adults with ASD but there is little evidence to provide specific comparative advice on effectiveness and safety.

The use of alternative strategies for behavioural difficulties, including behavioural and psychological approaches, environmental modification to ensure safety of the child and others, and adequate provision of respite care, should always be considered before using pharmacotherapy. However, it is also acknowledged that many behavioural procedures are also of unknown efficacy and safety. These approaches can be time consuming, expensive and stressful for the child and/or the child's family and whānau.

There are very few well-controlled studies of medications in ASD, particularly in children and adolescents. However, some evidence is accumulating for treatment of both aspects of core autistic symptomatology (largely compulsive and repetitive patterns – the 'cluster c' symptomatology of DSM IV) and frequent co-morbid symptoms, including anxiety and aggression. Of necessity, therefore,

many recommendations are based on short-term studies or expert opinion. Many medications utilised for children and adolescents with ASD have been developed for and tested in adults. Because of important potential differences in pharmacokinetics (metabolism etc) and pharmacodynamics (effects on the body and mind), findings from the adult literature should be applied to children and adolescents with significant caution. Studies involving children and adolescents are slow to take place and numbers included in studies small. Prescription of many agents will, by necessity, therefore be 'off-label' when applied to children with autism (that is, outside manufacturers' recommendations).<sup>300</sup> Parents, carers and professionals need to be aware of the implications of this practice.

In addition, the response to medications used to treat co-morbidities may be different for children with ASD so that special care is needed when prescribing in this group. For example, many children with ASD have coexisting significant ADHD symptomatology. While this may often improve significantly with stimulants, stimulants may increase anxiety and stereotyped behaviour. Stimulants may therefore be less useful in some children with autism. There is evidence that suggests that some children with ASD become over-focused when on stimulant medication, and repetitive and obsessional behaviour may be exacerbated.<sup>301</sup>

Clearly, for reasons of brevity, this review cannot address the vast literature on the use of psychoactive medications in disorders other than ASD. This means that any prescriber working with children with ASD must have a good working knowledge of psychiatric disorders, their diagnosis and treatment, and indeed of all psychoactive drugs, including their safety and efficacy. If the prescriber does not have this knowledge, then access to a child and adolescent psychiatrist or other appropriately knowledgeable prescriber is necessary. Where there is clear and properly diagnosed evidence of another mental health disorder (eg, ADHD), the child or person with ASD has should be treated according to evidence-based treatment guidelines for that disorder. However, prescribers must make it clear that the treatment may not improve ASD symptoms, and must ensure that there is monitoring for side effects (including worsening of ASD core symptoms like obsessional anxiety).

Some medications currently in use in children with ASD in New Zealand are relatively new medications. It is essential that both clinicians and parents appreciate that there is therefore very limited information on long-term safety. As children with challenging behaviour may remain on these medications for many years, both prescribers and parents need to understand that there is an element of risk in the use of such drugs.

The therapeutic use of a large number of different medications and other approaches such as biological agents and dietary approaches (*see section 4.5: Other interventions*) has been studied in ASD and related disorders, but not many are supported by rigorous evidence. Some of the studies have only assessed classes of medications, rather than individual agents. The most commonly studied agents are risperidone, fenfluramine, secretin and naltrexone. Some of the evidence for medications may be biased because the studies have been funded by the

manufacturers. Medications for which little or no evidence base exists are not necessarily less effective, but it is recommended that clinicians avoid using medications for which evidence of efficacy is not available.

A useful summary of issues in paediatric psychopharmacological prescribing may be found in a number of reviews by experts, although only the first of these is autism specific.<sup>302–304</sup>

## Adults

The evidence for psychotropic medications specifically for adults with ASD is extremely limited and consultation with specialists is recommended. Although there are specialists available for adults with intellectual disability and dual diagnosis (intellectual disability and mental health problems), there is a lack of specialists with specific knowledge of ASD.

Child and Adolescent Mental Health Services see young people until school leaving age. For Ongoing and Reviewable Resourcing Schemes (ORRS) funded students with significant disability, this may be the end of the year in which they have their 21st birthday. Once the young person has left school, services are provided by Adult Mental Health, according to the entry criteria of the particular service concerned. Where an individual, his or her caregiver or service provider thinks that the individual may benefit from the use of psychotropic medication, a consultation should be arranged with that person's general practitioner. If the general practitioner requires specialist advice she or he should contact the local adult mental health service and request advice or psychiatric assessment.

Regional Dual Disability Services (ie, Specialist Mental Health Services for adults who have a mental health disorder in addition to an intellectual disability) should be consulted where local primary and secondary services are unable to meet the individual's need.

**IMPORTANT NOTE FOR PRESCRIBERS:**

As prescribing information may change during the currency of this guideline, the guideline group has deliberately not provided full information about the status of medications in relation to registration, funding and manufacturer's recommendations. All prescribers must ensure that they are informed of current information in relation to the medications that they use and they 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 in relation to newly reported adverse effects and 'black box' warnings.

**4.4.a Managing specific symptoms and co-morbidities**

The choice of drug should be guided by the clinician's assessment of the symptom to be targeted by the intervention. Table 4.1 indicates which group of medications may be considered for a range of target symptoms.

**Table 4.1: Psychotropic medications used in the management of specific symptoms**

Symptom/core feature	Medications to consider
Anxiety	SSRI*
Repetitive/compulsive behaviour	SSRI
Stereotypies	SSRI, antipsychotic medications
Social interrelatedness/emotional reactivity	SSRI
Aggressive outbursts	Antipsychotic medications
Self-injurious behaviour	Antipsychotic medications, SSRI
Irritability	Antipsychotic medications
Attention deficit hyperactivity symptomatology	Stimulants, clonidine
Bipolar disorder	Mood stabilisers
Epilepsy	Anti-epileptic medications

\* SSRI = Selective Serotonin Re-uptake Inhibitor

The evidence for each group of medications is discussed below.

## Antidepressants

### Selective Serotonin Re-uptake Inhibitors (SSRIs)

One small randomised controlled trial (RCT) demonstrated a positive effect of fluoxetine on repetitive behaviour in children and adolescents with ASD.<sup>305</sup> A number of open-label studies have reported positive responses to fluoxetine (Prozac) and other selective serotonin re-uptake inhibitors (SSRIs). These responses include improvement in social interaction and emotional reactivity, reduction in stereotypies and obsessiveness, widening of range of interests and improvement in fluidity of movement. There are reports that the SSRIs may be helpful for children with ASD who exhibit high anxiety (*Recommendation 4.4.1*). A Cochrane systematic review on the use of SSRIs in ASD is in progress by Wheeler and colleagues at Children's Hospital at Westmead.<sup>306</sup> This review is currently at the stage of gathering information from authors and critical appraisal of papers and will not be available for inclusion in this version of the New Zealand ASD Guideline.

The SSRIs as a class have a number of usually minor and/or short-lived side effects, as listed in the various manufacturers' data sheets. These include:

- insomnia or sleep disturbance
- behavioural excitation and agitation
- dyskinesias or movement disorders
- withdrawal symptoms (these can occur if these drugs are stopped abruptly or doses are missed). They are more likely with those SSRIs that have a shorter duration of action, such as paroxetine.
- gastrointestinal upset
- loss of libido (in adolescents)
- weight loss.

Infrequent but serious side effects may include:

- serotonin syndrome (particularly if SSRIs are given with other serotonergic drugs or drugs which interfere with liver cytochrome metabolism)
- an increase in suicidal thinking in children and adolescents with mood disorders (notably paroxetine). It should be noted that there has been no evidence of an increase in completed suicide and there is ongoing research into the relationship between use of SSRIs in adolescents and suicidal thinking.

Note that research on the use of the SSRI citalopram for children and young people with ASD was comprehensively updated as part of the living guideline process, and is summarised in Appendix 10.2, and available as full text from the Ministry of Health website<sup>13</sup> (*Recommendations 4.4.1a and 4.4.1b*).

### Heterocyclic antidepressants

Two double-blind controlled studies have been undertaken comparing clomipramine (a tricyclic antidepressant with serotonin re-uptake inhibition) with desipramine (a tricyclic antidepressant without serotonin re-uptake inhibition) and placebo.<sup>307 308</sup> Clomipramine was significantly more effective in reducing obsessive compulsive behaviours than either desipramine or placebo. Desipramine is more likely to be cardiotoxic than clomipramine.

A later study compared clomipramine with haloperidol, and found haloperidol to be superior in terms of symptom control and also to be better tolerated.<sup>309</sup>

In relation to the use of heterocyclic antidepressants in children with ASD, there is insufficient evidence to make any recommendation (*Recommendation 4.4.2*).

## Antipsychotics

### Atypical antipsychotics

Of the atypical antipsychotics, risperidone is the most widely studied. A number of randomised controlled trials (RCTs) suggest that risperidone may be useful for children and adolescents with ASD who have serious behavioural problems (*Recommendation 4.4.3*). The Research Units on Paediatric Psychopharmacology Autism Network demonstrated that risperidone was effective and well tolerated for the treatment of tantrums, aggression and self-injurious behaviour in children and adolescents with autistic disorder.<sup>310</sup> Double-blind placebo-substitution withdrawal of risperidone indicated that risperidone discontinuation was associated with a rapid return of disruptive and aggressive behaviour in most subjects.<sup>311</sup> The same group also reported that risperidone resulted in significant improvements in the restricted, repetitive and stereotyped patterns of behaviour, interests and activities of autistic children but that it did not significantly improve deficits in social interaction and communication.<sup>312</sup> Similarly, another study found that risperidone significantly reduced irritability and other behavioural symptoms in children with ASD.<sup>313</sup>

While there is good evidence that risperidone is effective in reducing serious behavioural problems in children with ASD, randomised trials and a number of single case reports document a number of significant potential adverse effects.<sup>314–317</sup> A number of other atypical antipsychotic medications exist, although no RCTs relating to their use in ASD have been found by the Guideline Development Team (*Recommendation 4.4.4*).

Note that Recommendation 4.4.4 was revised following a comprehensive update of research on the use of the atypical antipsychotic aripiprazole for children and

young people with ASD as part of the living guideline process. This is summarised in Appendix 10.2, and is available as full text from the Ministry of Health website.<sup>13</sup> It is now acknowledged that while risperidone should be the first medication used when indicated for significant irritability in children and young people with ASD, aripiprazole could be used as a second-line treatment where individuals have demonstrated poor efficacy to risperidone or where there is concern regarding significant metabolic or adverse effects. Clinicians prescribing these drugs need to keep up to date with current literature (*Recommendation 4.4.4*).

Clinicians must be alert to the potential adverse effects of this group of medications. These include:

- significant weight gain
- sedation
- extra-pyramidal motor symptoms (eg, dyskinesias) which are dose-related
- hyperprolactinaemia. This can result in osteoporosis. It may also result in breast enlargement and occasionally secretion of milk in both males and females which can cause both alarm and embarrassment to the patient and carers. Monitoring prolactin levels has been suggested.

Clinicians should also be aware of the interaction with SSRIs if prescribing these medications concurrently.

### Haloperidol and other typical antipsychotics

Haloperidol has previously been frequently prescribed for individuals with ASD. The efficacy of haloperidol in reducing motor stereotypies, temper tantrums and improving social relatedness is not in doubt.<sup>318 319</sup> However, haloperidol and the other older antipsychotic agents have a high rate of side effects, especially dyskinesias (abnormal motor movements).



In one large study more than 50% of individuals developed dyskinesias (32% acute; 5% after chronic treatment and 15% on discontinuation). The withdrawal type dyskinesias (a variant of tardive dyskinesia) were noted to gradually abate after some months.<sup>320 321</sup>

The use of new agents such as risperidone with better safety profiles should be considered first before using older agents. These older agents should be reserved for cases where the beneficial effect of atypical antipsychotics is conspicuous but side effects such as weight gain are unacceptable. Haloperidol, in particular, has been shown to cause little weight gain. Thioridazine should only be used only in exceptional circumstances, as recent reports have implicated thioridazine in cases of sudden death<sup>322 323</sup> (*Recommendation 4.4.5*).

### Stimulants

Two stimulant drugs are available for use in New Zealand: namely methylphenidate and dextroamphetamine. These are class A controlled drugs (*see table 9.1, Appendix 9*) and are used off-label unless treating ADHD diagnosed according to DSM IV criteria, and other named conditions as specified in The Pharmaceutical Schedule. Three randomised controlled studies (including a total of 95 children) and two cohort studies (one publication, including a total of 226 children) examining the use of methylphenidate in children with ASD were identified.<sup>301 324–326</sup> The trials reported a significant improvement in ADHD-like symptoms, but no improvement in core ASD symptoms. Significant adverse effects occurred in some children, especially social withdrawal and irritability (*Recommendation 4.4.6*).

### Melatonin

Melatonin is a hormone produced in the human brain which regulates the sleep–wake cycle. Children with autism commonly have abnormal sleep patterns.<sup>327</sup> One non-randomised study of 15 children with Asperger syndrome and severe sleep problems demonstrated improvements in the sleep patterns in all cases.<sup>328</sup> A small controlled trial which was completed by only seven children showed improvement in sleep.<sup>329</sup> A large study (the MENDS study) has recently commenced in the United Kingdom. Results are expected by 2010.<sup>330</sup>

Melatonin is currently not registered for use in New Zealand. A number of different preparations can be purchased at retail pharmacies on presentation of a prescription. Caution is needed as formulations may vary and the appropriate dose is not clear (*Recommendation 4.4.7*).

Note that research on the use of the hormone melatonin for children and young people with ASD was comprehensively updated as part of the living guideline process, and is summarised in Appendix 10.2, and available as full text from the Ministry of Health website.<sup>43</sup> This review concluded that melatonin can be recommended for use in children and young people with ASD who are experiencing significant sleep problems, although longer term treatment requires further investigation. Behavioural strategies including sleep hygiene should be used in conjunction with melatonin (*Recommendations 4.4.7, 4.4.7a and 4.4.7b*).

### Clonidine

One small double-blind placebo-controlled crossover study reported improvement in hyperarousal behaviours in male children with ASD<sup>331</sup> (*Recommendation 4.4.10*).



### Sedatives

Benzodiazepines are sometimes used in emergency situations to effect sedation and manage very disturbed behaviour. There are insufficient data to recommend this practice routinely. Benzodiazepines have the potential to cause excessive sedation and disinhibition.<sup>332</sup> Some children and young people become agitated and aggression may increase after administration of benzodiazepines. Practitioners using these drugs should have appropriate training and experience (*Recommendation 4.4.10*).

Antihistamines are commonly used as sedatives in children. Trimeprazine (Vallergan) and promethazine (Phenergan) are both in use in New Zealand. These medications belong to the phenothiazine group of drugs and are used as antipsychotics. There is no autism-specific evidence for their use. These drugs, especially trimeprazine, can cause agitation. These drugs are not recommended for routine use (*Recommendation 4.4.10*).

### Mood stabilisers

Bipolar disorder occasionally occurs as a co-morbidity in children and adolescents with ASD. However, there are no controlled trials in the ASD population. No specific recommendation is made for pharmacotherapy of co-morbid bipolar disorder. This situation should be managed in consultation with an appropriately experienced psychiatrist (*Recommendation 4.2.8*).

### Antiepileptic medication

Epilepsy is relatively common in children with ASD, especially those with classical Kanner type ASD. Discussion of epilepsy management is outside the scope of this guideline. Children with ASD who also

have epilepsy should be managed in consultation with an appropriately experienced clinician.

Where children with co-morbid epilepsy also require pharmacological management of challenging behaviour, prescribers must consider both potential interactions between medications AND the potential for some psychotropic medications to lower seizure threshold (eg, fluoxetine, methylphenidate, and risperidone) (*Recommendation 4.2.9*).

### 4.4.b Non-established pharmacological agents

A number of other pharmacological agents have been discussed in the international literature as potentially useful for modifying various symptoms in ASD. Some of these agents have been used widely in the past (notably, fenfluramine, naltrexone and secretin). For some of these, there is insufficient evidence for effectiveness, but so far there is also insufficient evidence to prove that they are ineffective. For others, there is evidence that they are ineffective, and in some instances potentially or actually harmful. They are discussed here, to provide assistance to clinicians and parents who may read about these agents and wish to have further information about them. A number of these agents are not currently available in New Zealand. Use of any of these agents to treat children with ASD in New Zealand would be off-label and would be regarded as out of line with current standard practice in this country. None of these agents is recommended.

### Amantadine

Amantadine (Symmetrel) is a non-competitive N-methyl-d-aspartate (NMDA) receptor antagonist licensed in New Zealand for use as an antiviral agent and as an antiparkinsonian agent. One randomised controlled study was

identified.<sup>333</sup> This study found statistically significant improvement on some subscales (notably hyperactivity) on investigator ratings, but no differences on parent ratings (*Recommendation 4.2.11*).

### Immunoglobulins

One small double-blind placebo-controlled study on the use of intravenous immunoglobulins was reported in a letter to a journal but is difficult to evaluate.<sup>334</sup> The authors reported improvement on parent and teacher ratings but no difference on clinician ratings. They urged caution and recommended further research (*Recommendation 4.2.11*).

### Naltrexone

Naltrexone is an opioid antagonist. It is used in New Zealand in the management of opioid and alcohol dependence. It has largely been used in relation to repetitive self-injury in children and adolescents with ASD.

As with other agents, there are several case reports and open-label studies. Two double-blind placebo-controlled crossover studies, with very small numbers of children, were identified.<sup>335 336</sup> Results were inconsistent with improvement in teacher ratings (but not in parent ratings) achieving statistical significance in one study and the opposite finding in the other study (*Recommendation 4.2.11*).

### Fenfluramine

Fenfluramine (Ponderax) was previously available in New Zealand for use as an anorectic in obesity. It has been withdrawn because of concerns about safety. In the early 1980s there was substantial interest in the use of fenfluramine in ASD. Fenfluramine significantly lowers blood serotonin levels, which are elevated in a proportion of individuals with ASD (and

other developmental disorders). A non-systematic review concluded that, while there were many studies of this agent, there were some concerns about methodology, even in some trials described as double-blind and placebo-controlled.<sup>337</sup> A double-blind placebo-controlled trial was also identified.<sup>338</sup> While there are some data to suggest that fenfluramine enhances social relatedness and reduces stereotypies and overactivity, the results are not consistent. There have been significant concerns about potential neurotoxicity on the basis of animal studies as well as reports of significant adverse effects in humans and depletion of brain serotonin with long-term use (*Recommendation 4.2.12*).

### Secretin

There is no evidence to support the use of secretin (either human, synthetic or porcine) in children with ASD. There was an initial surge of enthusiasm over this medication in the 1990s, following a report that three children, who received secretin while undergoing gastroenterological investigations, had demonstrated improvement in their autistic symptomatology following infusion. Subsequent anecdotal reports and open-label studies appeared to confirm that secretin might be effective. There have now been several double-blind randomised controlled trials, all of which have demonstrated that secretin is ineffective<sup>339 340</sup> (*Recommendation 4.2.12*).

### Chelation therapy

There is no evidence that heavy metals are implicated in the causation of ASD. There are no randomised controlled trials of chelation therapy in children with ASD. Chelation therapy is potentially dangerous and, given the absence of evidence for benefit, should not be used<sup>341</sup> (*Recommendation 4.2.12*).

## 4.5 Other interventions

### Summary of recommendations

Recommendations:	Grade
<p>4.5.1 There is insufficient evidence to make any recommendation with respect to the use of the following biological agents, nutritional or other approaches for ASD-specific symptoms in children with ASD. The opinion of the Guideline Development Team is that these agents are unlikely to be useful:</p> <ul style="list-style-type: none"> <li>• combined vitamin B6–Mg</li> <li>• dimethylglycine</li> <li>• gluten and casein free (GCF) diet</li> <li>• omega-3/long chain polyunsaturated fatty acids</li> <li>• auditory integration training</li> <li>• holding therapy</li> <li>• options therapy</li> <li>• sensory integration therapies</li> <li>• Irlen lenses.</li> </ul>	I
<p>4.5.2 The use of Facilitated Communication for ASD-specific symptoms in children with ASD is not recommended.</p>	B

Over the past decades, a number of other approaches have been used as treatments and many have been claimed as ‘cures’ for ASD. Some of these are currently popular in New Zealand and are being promulgated by a very small number of medical practitioners. Most of the research in this area is based on anecdotal reports rather than controlled studies. The lack of quality research evaluating these treatments means that firm conclusions cannot be drawn about their effectiveness. For a small number of treatments, there is evidence that they are ineffective and, in some instances, potentially or actually harmful. Addressing all possible alternative treatments is beyond the scope of this guideline. The most common interventions are briefly discussed. The interventions include biomedical approaches and other alternative non-medical treatments.

### Biomedical approaches

Biomedical approaches seek to alter physiology or change the underlying processes that result in symptoms of autism. They include combined vitamin B6–magnesium (Mg), dimethylglycine, gluten-casein free diet and omega-3/long chain polyunsaturated fatty acids.

#### Combined vitamin B6–magnesium (B6-Mg)

A Cochrane systematic review (updated 2005) concluded that no recommendation could be made regarding the use of B6–Mg as a treatment for ASD.<sup>342</sup> Three small studies were included in the review (total n=33) but data were unsuitable for pooling (*Recommendation 4.5.1*).

**Dimethylglycine (DMG)**

Dimethylglycine is closely related to the inhibitory neurotransmitter, glycine. It is readily available from health-food shops in New Zealand. Rimland (of the Autism Research Institute in San Diego) has advocated its use and there are a large number of anecdotal reports that DMG is useful. Only one small randomised controlled trial was found.<sup>343</sup> This did not demonstrate significant differences between the groups (*Recommendation 4.5.1*).

**Gluten-casein free diet**

In a Cochrane systematic review (updated 2004) of gluten and casein free diets in ASD, only one small trial (n=20) met the criteria for inclusion.<sup>344</sup> Three of the four outcomes studied were not significant between groups but a benefit was found for one outcome, reduction in autistic traits, on parental report for participants randomised to the gluten-casein free diet compared to placebo. The reviewers concluded that these results added weight to the existing anecdotal evidence but that there was insufficient evidence for clinicians to advise the use of gluten-casein free diets for individuals with ASD and more adequately powered research was needed (*Recommendation 4.5.1*).

**Omega-3/long chain polyunsaturated fatty acids**

There is current interest in the role of polyunsaturated fatty acids (PUFA), especially omega-3 and omega-6 long-chain PUFA (LC-PUFA), in brain development and function. A Medline search in July 2005 did not yield any studies meeting our criteria for review. The use of these agents cannot currently be recommended (*Recommendation 4.5.1*).

Other biomedical treatments have been tried but there is either insufficient or no evidence to recommend them. These include electroconvulsive therapy and cranial osteopathy. None of these approaches can currently be recommended.

**Other alternative approaches****Facilitated communication**

Facilitated Communication was developed by Rosemary Crossley in Melbourne. The technique involves supporting the hand, wrist or arm of the communicator, pulling back the hand and, where necessary, helping to isolate the index finger while the person accesses a word, picture board or keyboard to communicate. Emotional support in the form of encouragement is also supplied by the facilitator. It is intended that the supports be faded over time. Some qualitative reports show people have become independent typists after training with Facilitated Communication.

There has been considerable controversy about whether the facilitated output is from the person with ASD or is under the influence of the facilitator. A large number of quantitative studies show facilitator influence.<sup>104</sup> There is no scientific validation of Facilitated Communication and it is not recommended (*Recommendation 4.5.2*).

**Auditory integration training (AIT)**

This is a procedure to retrain the auditory system in an attempt to address hearing abnormalities and to effect positive behaviour changes for people with ASD. Anecdotal reports of negative side effects, such as hearing loss, have raised a number of ethical questions regarding its use and it has been suggested that the nonstandardised and unregulated use of AIT may place individuals using this treatment at risk.<sup>345</sup> A Cochrane systematic review of AIT studies with a number of

methodological flaws concluded that there is no clear evidence for auditory integration therapy nor does the procedure provide beneficial changes to behaviours of people with ASD.<sup>346</sup> The review concluded that further research is required to determine the effectiveness of sound therapies and that, in the absence of evidence, the treatment must be considered experimental and parents should be made aware of the cost of treatment. The American Academy of Pediatrics also suggests that the use of AIT should be limited to research protocols.<sup>347</sup> No recommendations can be made for this treatment (*Recommendation 4.5.1*).

### **Holding therapy**

This intervention is based on the work of Tinbergen and Tinbergen<sup>348</sup> who claim that autism is caused by an emotional imbalance which results from a lack of attachment between the mother and the child with ASD, causing the child to withdraw inwards. Holding therapy requires the mother to provide intense physical contact with her child, even to the point of eliciting distress until the child submits and accepts comfort. No adequate research on this intervention has been undertaken (*Recommendation 4.5.1*).

### **Sensory integration (SI)**

Sensory integration therapy is based on the sensory integration theory developed by Jean Ayres in 1970. SI helps to reorganise the vestibular, tactile and proprioceptive systems and is intended to remediate perceived sensory difficulties to allow the child to interact with the world in a more adaptive fashion. Sensory integration theory lacks empirical support. There are no experimentally sound studies supporting the use of sensory integration in the treatment of children with ASD<sup>349</sup> (*Recommendation 4.5.1*).

### **Irlen lenses**

This therapy is based on the notion that children with ASD may have overstimulated cells in their retinas or abnormalities in the optical neural pathways which result in incorrect signals being sent to the brain. The treatment involves the placing of coloured overlays or lenses over printed pages to allow the correct interpretation of visual stimuli. Some subjective reports have found benefits for students with ASD,<sup>350</sup> but there is no conclusive evidence of effectiveness (*Recommendation 4.5.1*).

A number of other treatments have been tried. They have either not been assessed in controlled studies or studies have not found evidence that they are effective. More research is required before conclusions can be reached about these treatments. These include:

- pet therapies (such as service dogs, horse riding)
- dolphin-assisted therapy
- the Dolman-Delacato method
- horticulture
- aromatherapy.<sup>42 266</sup>

## 4.6 Supporting people with challenging behaviour

### Summary of recommendations

Recommendations:		Grade
4.6.1	When challenging behaviours are evident, people with ASD need to be assessed for co-morbid conditions such as seizures, ADHD, anxiety disorders, depression and gastrointestinal problems ( <i>see Appendix 10.4</i> ).	C
4.6.2	In severe or life-threatening situations, medication may be the optimum therapy.	C

Good Practice Points:		
4.6.3	There should be access to interagency, multidisciplinary teams for ongoing serious behaviour needs.	✓
4.6.4	<p>The following systems need to be in place for emergency situations and there must be a prompt response:</p> <ul style="list-style-type: none"> <li>specialist staff with skills and experience in ASD from all relevant professions available for consultancy</li> <li>a multiagency team which can work in education settings and coordinate with home and community based interventions</li> <li>facilities to withdraw a child from class when they are, or are likely to be overloaded</li> <li>24-hour care placement for a small number of children and young people who cannot be accommodated within school and home. This should be regarded as a last resort and be for as short a period as possible.</li> </ul>	✓
4.6.5	Referral to the High and Complex Needs Intersectoral Unit (children and young people), Adult Mental Health, and/or local Needs Assessment and Service Coordination agencies may be required when behaviour is challenging.	✓

Even with well constructed and implemented behavioural interventions (as outlined above), a small number of children, young people and adults with ASD may develop very serious or dangerous behaviours.<sup>102</sup> Extreme behaviours that put the person with ASD, others or property at serious risk will require assessment by specialist behaviour professionals and will usually require a multidisciplinary team from different agencies (*Good Practice Point 4.6.3*). Such a team will require good service coordination if it is to be effective.<sup>11</sup> When challenging behaviours are evident, people with ASD may need to be assessed for co-morbid conditions such as seizures, ADHD, anxiety disorders, depression<sup>11 104</sup> and gastrointestinal disorders (*Recommendation 4.6.1*). Although medications are not regarded as the treatment of choice for behaviour problems, this may need to be considered for severe or life-threatening situations<sup>11 104</sup> (*Recommendation 4.6.2*). Behavioural interventions may enhance the use of medication<sup>104</sup> and expert opinion suggests that medication may enhance receptiveness to behavioural interventions.

Schools, families and whānau, and services supporting people with extreme behaviour problems need rapid access to specialist assistance and support for staff, families and whānau (*Good Practice Point 3.2.5.5, section 3.2.e*). A timely response may prevent loss of current residential, educational and vocational placements.<sup>11</sup>

Systems which need to be in place to support a crisis response include:

- specialist staff with skills and experience in ASD from all relevant professions available for consultancy
- information for people with ASD, parents, family and whānau, and professionals about how to access consultancy and support from specialist staff
- a multiagency team which can work in all settings
- short break respite (with specific ASD knowledge) and other respite in-home supports for families
- facilities to withdraw a person from a situation when they are, or are likely to be, overloaded
- 24-hour care placement for a small number of people<sup>11</sup> (*Good Practice Point 4.6.4*).

For some children and young people who have exceptional needs across two or more sectors, a referral to the High and Complex Needs Intersectoral Unit may be appropriate (*Good Practice Point 4.6.5*). A successful referral would result in a suitable person being appointed to coordinate the team's support plan. Extra funding is provided to resource the plan. Similarly, adults with ASD who exhibit challenging behaviour should be referred to Adult Community Health, and, if intellectually disabled, to local Needs Assessment and Service Coordination agencies (*Good Practice Point 4.6.5*).



## 4.7 Crisis management

### Summary of recommendations

Good Practice Points:		
4.7.1	Appropriate support should be promptly delivered at times of crisis.	✓
4.7.2	Proactive crisis support planning should be routinely undertaken and reviewed on a regular basis.	✓
4.7.3	The development of crisis services should be investigated.	✓

Crises come in many forms. Previously settled children, young people, and adults with ASD may move into a situation of crisis for any number of reasons. Change is a known trigger for crisis, but the impact of changes that can be predicted (eg, transitions, staff redeployment, terminal illness of an important person), may be able to be well managed, with adequate planning, support and service provision.<sup>351</sup> Crises caused by sudden (such as a change in circumstances, for example, family illness, injury or death) and unpredicted (sometimes unknown) factors can have a devastating effect on the emotional, mental and behavioural wellbeing of a person with ASD,<sup>26</sup> and serious implications on their educational or work placements, living situations, independence, health and safety.

Very little research or information was identified pertaining to crisis management for people with ASD, and this area of support requires further attention. However, prompt provision of appropriate support during times of crisis appears vital (*Good Practice Point 4.7.1*). Given the distinctive needs of people with ASD, no one system is likely to meet the needs of all people. Therefore, proactive crisis support planning should be routinely undertaken and reviewed on a regular basis (eg, annually) (*Good Practice Point 4.7.2*). Planning should consider any/all predictable changes or other stressors, and

the potential impact of a sudden and unpredicted stressor. Attention to the following factors is recommended:

- how their experience of stress can be minimised
- the potential need for accurate information about the person to be conveyed to others (eg, relevant background, up-to-date medical records, communication systems, response to previous interventions, personal preferences, key professional personnel) in a timely manner
- where the person is best supported (in which environment)
- who should support them
- how much support may be required
- how parents, families and whānau, schools and agencies will work together to minimise the impact of the crisis
- lead agencies and professionals
- the role of medication
- funding arrangements (*Good Practice Point 4.7.2*).

Because of concern about the experiences of people with ASD as mental health inpatients, alternatives to inpatient care have been recommended.<sup>47</sup> Crisis services have been recommended that involve staff trained in ASD and that contain timely and



flexible systems that are able to adapt to the needs of the person in crisis and minimise the need for in-patient care<sup>47</sup> (*Good Practice Point 4.7.3*). Other additional characteristics of ideal crisis services include:

- systems that reduce external pressure, perhaps by reducing choices, providing structure and avoiding confrontation or arguing
- community-based homes, if out-of-home placement is needed rather than in-patient facilities
- staff teams that visit people with ASD in their own homes, and are also accessible to families
- consistent approaches and clear communication within services, and between the service and other relevant agencies (ie, mental health specialists, police, probation, youth offending, lawyers)
- a training role with other relevant agencies to ensure that they are appropriately responsive to people with ASD<sup>47</sup> (*Good Practice Point 4.7.3*).

## 4.8 Mental health, forensic and disability services

### Summary of recommendations

Recommendations:	Grade
4.8.1 Adults with ASD who are patients of adult mental health or forensic services should be supported to overcome fears and given information on their rights and advocacy services.	C

Good Practice Points:	
4.8.2 People with ASD experiencing serious mental health disorders should be supported by mental health services appropriate to their age or situation.	✓
4.8.3 The development of ASD-specialist teams within mental health services should be investigated.	✓
4.8.4 When hospitalisation in mental health services is needed on a recurring basis, whenever possible the same hospital unit and key personnel should be used.	✓
4.8.5 People with ASD (with or without an additional disability) should be referred to their local Needs Assessment and Service Coordination (NASC) agency.	✓
4.8.6 Adults with ASD, intellectual disability and mental health problems should be referred to specialist Dual Diagnosis Services (intellectual disability and mental health) through their GP or local Adult Mental Health Service.	✓
4.8.7 Adults with ASD and intellectual disability, and who are charged with or convicted of a crime, should be referred to Forensic Intellectual Disability Services, either through Adult Mental Health Services or NASC agencies.	✓

### Mental health services

All children and young people with ASD who are experiencing mental health problems should access clinical services through local Child and Adolescent Mental Health Services (CAMHS) (*Good Practice Point 4.8.2*). Although professionals working in these services certainly have professional learning and development needs (see Part 6, *Professional learning and development*), some of them will be experienced in working with children and young people with ASD. The development of ASD-specialist teams within CAMHS may be appropriate (*Good Practice Point 4.8.3*).

Adults with ASD who are experiencing mental health problems should access clinical services through General Practice or, where mental health problems are severe, through local Adult Mental Health Services (*Good Practice Point 4.8.2*). In circumstances when adults with ASD have been charged with or convicted of committing a crime whilst believed to be mentally unwell, they may receive services from Forensic Mental Health Services (*Good Practice Point 4.8.2*). However, ASD was traditionally seen as a childhood disorder, and interest in the spectrum by specialists in adult and forensic mental health is a recent development. Consequently, some writers have identified significantly more training and professional learning and development needs for adult and forensic mental health professionals, including psychiatrists,<sup>47 293 294</sup> and across a variety of sectors (eg, in-patient units, community services and secure services). However, no research was identified that addressed this issue. The development of ASD-specialist teams within Adult and Forensic Mental Health Services and CAMHS may be appropriate (*Good Practice Point 4.8.3*).

Negative experiences of adults with ASD within adult mental health and forensic systems are described in clinical settings, reviews,<sup>270</sup> and reports by the people themselves.<sup>33</sup> Reluctance to have contact with or be an in-patient of adult or forensic mental health services is common, as are fears of being misunderstood, misdiagnosed, and inappropriately medicated or hospitalised.<sup>270</sup> Once these fears are addressed and the professional learning and development needs met, adult mental health and forensic services may well be appropriate sources of support for adults with ASD who experience mental health problems<sup>48 270 294</sup> (*Recommendation 4.8.1*). Consistency of environment and staffing may minimise stress for people with ASD when hospitalisation in mental health services is needed on a recurring basis (*Good Practice Point 4.8.4*).

### Disability services

People with ASD who have an additional disability may be entitled to Disability Services, through the Ministry of Health. Access to such services is managed by local Needs Assessment and Service Coordination (NASC) agencies, contacts for which are available from the Ministry of Health.

People with ASD who also have an intellectual disability may be able to access the full range of services for children, young people and adults with an intellectual disability. Access to intellectual disability services is also managed by NASC agencies (*Good Practice Point 4.8.5*). People with ASD, intellectual disability, and mental health problems may access specialist Dual Diagnosis Services (intellectual disability and mental health) through their GP or local Adult Mental Health Service (*Good Practice Point 4.8.6*). People with ASD and intellectual disability, and who are charged with or convicted of a crime, may access Forensic Intellectual Disability Services, either through Adult

Mental Health Services or NASC agencies (*Good Practice Point 4.8.7*) (also see *section 5.3.b: People with ASD suspected, accused, charged or convicted of crimes*).

While staff working within intellectual disability services also have ASD-related professional learning and development needs (see *Part 6: Professional learning and development*), a significant number of professional staff have relevant experience of ASD within the population of people with an intellectual disability.



## Part 5

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### Living in the community

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

## **Part 5 Living in the community**

This section of the ASD Guideline addresses the support needs of people with ASD in the community that fall beyond the scope of initial diagnosis and early childhood/school education services. These include transition into adulthood, further education and work (paid or unpaid), recreation and leisure, and contact with the police, courts and criminal justice systems.

## 5.1 After secondary school

### Summary of recommendations

Recommendations:		Grade
5.1.1	Research should be undertaken to identify appropriate methods of supporting people with ASD when they leave school.	C
5.1.2	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
5.1.3	Further and post-compulsory education should be considered as an option for all people with ASD, regardless of their intellectual ability.	C
5.1.4	Planning for transition into further and post-compulsory education should consider symptoms of ASD that may have an impact in these settings, and aspects of educational environments that may complicate transition and known support strategies.	C
5.1.5	People with ASD should access appropriate student services.	C
5.1.6	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
5.1.7	Providers of further and post-compulsory education should recognise that people with ASD may have special requirements when being formally assessed and take these into account in their policies and procedures.	C
5.1.8	Work (paid and unpaid) should be considered as an option for all people with ASD, regardless of their intellectual ability.	B
5.1.9	Any known support needs of people with ASD, including those relating to cognitive ability, should be taken into account when transitioning into any work environment ( <i>see Appendix 10.3</i> ).	B
5.1.10	Supported employment services for people with ASD should be developed ( <i>see Appendix 10.3</i> ).	C
5.1.11	Supported employment services should incorporate known features of best practice employment for people with an intellectual disability and ASD-specific strategies ( <i>see Appendix 10.3</i> ).	B
5.1.12	Any characteristics of ASD that may have impact in the work setting (both as strengths and as needs) should be taken into account when planning transition into work, when making choices about work and career and in accessing ongoing in-work support ( <i>see Appendix 10.3</i> ).	B
5.1.13	Supported employment services should work with employers, managers and colleagues to maximise success in work placements ( <i>see Appendix 10.3</i> ).	B

Recommendations:		Grade
5.1.13a	Supported employment services are recommended and should be available for all people with ASD ( <i>see Appendix 10.3</i> ).	B
5.1.13b	Supported employment services should make available, where required: <ul style="list-style-type: none"> <li>• Individualised job matching based on the person's career goals, strengths, and interests</li> <li>• Pre-placement assessment of work tasks and work environment</li> <li>• Promoting understanding of any support needs within the work environment, including training employers and colleagues in the goals, processes and benefits of supported employment services.</li> <li>• On-the-job provisions, including training of work tasks, acclimatisation to the work environment, social integration, developing communication and interpersonal skills, and management of stress and any contextually inappropriate behaviour</li> <li>• Job coaches with level of support is determined by need</li> <li>• Work place modifications</li> <li>• Long-term support in developing natural supports (eg, upskilling managers) and, where needed, external supports (eg, follow-up, assisting with issues which impact on work) (<i>see Appendix 10.3</i>).</li> </ul>	B
5.1.14	Vocational services of a high standard should be available for people with ASD who are not ready or able to access education or work.	B

Good Practice Points:	
5.1.13c	Methodologically rigorous research is greatly needed to examine and improve the effectiveness of New Zealand-based supported employment services for people with ASD ( <i>see Appendix 10.3</i> ). ✓
5.1.13d	New Zealand based research should consider the effectiveness of supported employment services for people of different ethnicities with ASD ( <i>see Appendix 10.3</i> ). ✓
5.1.15	Self-employment may be an appropriate option for some people with ASD. ✓
5.1.16	More research is required on self-employment options for people with ASD. ✓



### 5.1.a Leaving school

Given that restricted, stereotyped and repetitive repertoires of interests and activities are key features of people with ASD, it is unsurprising that many experience significant stress when their routines are changed and their normal support systems are disrupted.<sup>352</sup> Leaving school alters the environments in which people spend their time, what they do and when they do it. It also changes the people with whom they share their day or interact. Accordingly, leaving school can be a highly anxious time, not just for the person with ASD, but also for his/her parents and family. The situation is further complicated by the cessation of relationships/contact with people who have provided formal support within the high school system (often for long periods of time), and the prospect of unemployment, under-employment and lack of meaningful daytime activity. Whilst little research covering this transition was identified (*Recommendation 5.1.1*), expert opinion suggested that successful transition requires considerable care and time<sup>352–355</sup> (*Recommendation 5.1.2*).

Careful transition planning has been recommended to minimise the anxiety that people with ASD and their families experience when time comes to leave school<sup>353 354 356</sup> (*Recommendation 5.1.2*). Attention to the attachments that the individual with ASD has with their school (environments and people) is important so that the timing, sequencing and synchronisation of leaving school (and of other transitions) can be carefully planned.<sup>352</sup> Suggestions to increase the chance of successful transition into further education or work (paid and unpaid) include:

- taking a person-centred planning approach to transition

- facilitating self-determination, to ensure that the wishes of the person with ASD are fully taken into account
- careful selection of course of study or type of work
- careful selection of place of study (type of further education provider, geographical location, level of support offered to students) or employer
- coordination between the education sector and funders of adult services
- precise timing of funding, because the person may need to transition gradually, and possibly attend both the high school and the further education organisation, or work, on a part-time basis
- flexibility of commencement of further education or work, so that the person can become familiar with the environment and new demands, whilst not being overloaded
- anticipation of problems and creative problem solving (eg, of how to manage timetables, spare time, the social demands of further education or the workplace).<sup>47 352–354 357 358</sup>

### 5.1.b Further (post-compulsory) education

Further education should be an option for all people, regardless of ability or disability (*Recommendation 5.1.3*). In fact, improved post-compulsory education options for all disabled people is a significant action listed in the New Zealand Disability Strategy.<sup>359</sup> Nevertheless, people who are different sometimes experience barriers when trying to access further, post-compulsory education,<sup>358</sup> and, in the past, the educational options and outcomes for people with ASD were poor.<sup>270 356 360</sup> Over recent years, as ASD has become more readily diagnosed and better managed and supported within schools, educational outcomes have improved.<sup>360</sup> Improvement

may also be related to legislative changes in many parts of the world that recognise and support the rights of people with a disability to self-empowerment and participation in all aspects of society.<sup>270 356 359</sup>

People with ASD do have the potential to have successful and satisfying experiences in further education, regardless of their intellectual level.<sup>356</sup> The chances of this are enhanced with careful planning and attention to ASD-specific issues (*Recommendation 5.1.2*). Symptoms of ASD that may have significant impact in further and post-compulsory educational settings and should be considered in the planning process include:

- problems making friends and maintaining friendships, causing possible social isolation and difficulty working in a group
- lack of initiative, and lack of or failure to use self-help and independence skills
- low self-esteem and poor self-confidence
- peculiar use of language (eg, unduly dull speech, monotonous voice, over-precise grammar and vocabulary, using complex words without fully understanding their meaning)
- literal understanding of language
- intense interest in select topics, and resistance to changing an area of study
- unawareness of the needs and emotions of other students or education staff or both
- insistence on routine and sameness, and intense overreaction to change
- poor non-verbal communication (eg, limited facial expression, inappropriate eye contact, lack of understanding of sarcasm or irony)

- clumsiness, poor coordination and gross motor skills, ungainly movement, difficulty mastering practical skills
- unrecognised onset of co-morbid mental health problems<sup>47 361</sup> (*Recommendation 5.1.4*).

Aspects of post-compulsory and tertiary education environments can complicate transition into these settings, especially for people with ASD.<sup>48 356 362</sup> Further education settings can be large, crowded and noisy. Within them, people often move from one room to another. Verbal communication is a predominant means of teaching, and sessions can vary in form, from traditional lectures by teaching staff, to student-led seminars, laboratory and fieldwork and informal experiential or tutorial groups (*Recommendation 5.1.4*). Changes within the services provided by some of the post-compulsory and/or tertiary educational organisations across New Zealand reflect their shared responsibility to people with ASD to maximise the chances of successful educational experiences. New Zealand universities and polytechnics have student service departments through which students can access a wide range of support, ranging from study skills and counselling to note-taking and examination assistance (*Recommendation 5.1.5*). Information is available through the organisations' websites and some include specific ASD policies<sup>363</sup> and ASD support groups.<sup>364</sup>

There are a number of strategies that could be considered when any person with ASD is transitioning into further and post-compulsory education and, periodically, for ongoing support. Some of them can be accessed through student service departments, but when these services are deficient, appropriate support may need to be organised from another source. Support strategies include:

- vocational counselling and course selection
- buddies/guides for first-year students to help them settle in
- study skills support and development (eg, planning and sticking to a study and assignment schedule)
- practical resources (eg, rest and study rooms, computer access)
- mentoring
- counselling (eg, dealing with the social demands of tertiary life, learning skills of self-organisation and problem solving, managing anxiety, controlling obsessive interests)
- one-to-one tutors or assistants
- reformatting course materials
- audiotaping lectures or arranging for a note-taker
- alteration of personal routines to suit study and attendance requirements
- informing staff of ASD diagnosis, and obtaining appropriate assistance
- examination support<sup>47 361–369</sup> (*Recommendation 5.1.4*).
- beginning sessions by introducing the specific learning outcomes for that session
- using an authoritative (not authoritarian) style and consistency
- patience, respect, fair play, support and encouragement
- assisting a student to stay on task by reminding them that the task at hand is an important step in developing their knowledge
- organising short breaks in long sessions, and on occasions when the student has difficulty
- discussing challenges with the student counsellor and/or line manager
- progressing review of learning outcomes towards the end of the course, so that transition can be planned (*Recommendation 5.1.6*).

One United Kingdom guideline for people with Asperger syndrome<sup>47</sup> provides specific advice to tutors and lecturers and recommends:

- establishing clear learning outcomes at the beginning of the course
- establishing class rules and making behavioural expectations explicit at the beginning of the course
- reminding students of class rules and behavioural expectations when necessary
- using a clear and standardised framework for each teaching session
- Expert opinion suggests that people with ASD can experience great stress at examination time, which interferes with their ability to demonstrate clearly the knowledge and skills they have acquired.<sup>368</sup> It is possible to alter examination arrangements to minimise stress and maximise opportunities for performance, yet maintain the integrity of the examination. Useful examination considerations and adaptations for written examinations include:
  - informing the student of the date, time and duration of the exam well in advance
  - if possible, telling them the location and which staff will be adjudicating
  - giving an estimation of how many other people will be sitting the exam
  - drawing a plan of how the chairs and desks will be arranged (and seating plan, if possible) if this is a source of anxiety for the student

- being specific about the topics and modules being tested
- giving the student the opportunity to arrive at the exam early, so they can become comfortable with the environment
- recognising that the student may need the adjudicator to instruct him/her personally
- considering allowing the student to take the examination in a separate room (with supervision), away from the distraction that test taking with others provides and to ensure that others are not distracted by the student with ASD
- permitting the student to have an object of comfort in the examination room
- granting extra time in advance of the examination day, as many people with ASD find it extremely hard to work within a time limit, or experience such stress at having a time limit that they cannot perform at their optimum level
- ensuring the student knows they are free to leave the room when they have finished their examination paper
- presenting examination papers in a manner that is not distracting (eg, certain colours can be very distracting for some people, who may work better when examination papers are plain or uncoloured)
- ensuring that instructions and questions are clear and unambiguous, and avoid abstract ideas, except when understanding such ideas is part of the assessment
- prompting obsessional students when it is time to move on to the next question, to avoid unnecessary and obsessional rewriting of answers
- allowing use of a word processor if handwriting is extremely slow

- arranging for scrutinisation of answer papers by an educational professional with expertise in ASD if there are concerns that the student's performance may not reflect their ability (the scrutineer could comment on the general appearance of the paper, including diagrams and labelling, language used, obsessional content of the answers and possible use of inappropriate language)<sup>47 368</sup> (*Recommendation 5.1.7*).

Oral examinations can be particularly difficult for the person with ASD, and for examiners if they are unaware that the student has ASD.<sup>368</sup> The National Autistic Society<sup>47 368</sup> suggests that oral assessment over a period of days rather than hours should be considered, and that examiners should be briefed that the candidate may display some of the following behaviours:

- poor understanding of body language
- standing/sitting too close – invasion of 'personal space'
- inappropriate or poor eye contact (ie, avoiding or over-intense)
- unusual physical movements or walking around
- making inappropriate remarks, that are either over-familiar or too formal
- repeating questions, including copying the voice and accent
- hesitant or disjointed speech, unless the topic is of obsessional interest to the student
- failure to understand abstract ideas
- literal understanding of jokes, exaggerations and metaphors
- poor understanding of questions about relationships and social situations (*Recommendation 5.1.7*).

### 5.1.c Work (paid and unpaid)

Work is one of the primary activities of adults in our society, and with work comes status, success and other related benefits. Adults with ASD often experience difficulty securing and maintaining work. Long periods of unemployment are common, as is 'under-employment', or working below one's skills level.<sup>33 34 270 355 370 371</sup> A systematic review of outcomes in adult life of more able people with ASD concluded that few specialist support systems existed for adults with ASD, and that most individuals relied heavily on the support of their families in finding jobs.<sup>360</sup> Anecdotal evidence suggests that this conclusion is applicable to New Zealand. Furthermore, research into, and systematic reviews of, the employment options and experiences of people with an intellectual disability (many of whom may also have ASD) found similarly disappointing results and unsatisfactory experiences.<sup>358</sup>

To become a worker is a normal life goal. For a person with ASD, whatever their ability level, becoming a worker is more likely to be achieved with careful attention to preparation and planning.<sup>270 354 355 357 360 370–375</sup> (*Recommendations 5.1.2 and 5.1.8*). The support needs of people with disabilities, including ASD, fall into six broad areas: assistance in finding a job (recruitment), learning how to do the job, obtaining assistance with completing the job, addressing work-related issues, addressing non-work-related issues and transportation<sup>376</sup> (*Recommendation 5.1.9*). People with an intellectual disability who receive relevant work experience as part of their school-based transition planning are more likely to maintain competitive jobs.<sup>358</sup> However research suggests that the responsibility for 'making it work' in an employment setting tends to rest on the person with ASD, rather than the employer.<sup>377</sup> While advice especially designed for use by people with ASD

exists,<sup>355</sup> strategies are typically targeted towards supported employment services for people with ASD.<sup>357 370–372 376 378</sup>

Positive work outcomes (eg, increased chances of finding work, maintaining work and having good working relationships) for people with ASD (including those with co-morbid intellectual disability) are more likely when supported employment services are involved.<sup>357 358 373–376 379</sup> (*Recommendation 5.1.10*). Involvement of supported employment services has also been associated with improved attitudes of employers towards people with ASD, in that they are more likely to rate the employee's effectiveness at their job, rather than their ability to work in an established way and to adapt to the organisation, and more likely to be willing to be supportive and adapt circumstances to suit the person concerned.<sup>377</sup>

Features of best practice identified in a review of intellectual disability and ASD supported employment literature<sup>357</sup> include:

- individuals controlling their own vocational destinies through self-determination, facilitated by person-centred planning, and a career-based approach
- employment coaches acting as facilitators, not experts
- taking account of employers' as well as individuals' needs
- using 'natural supports' and supplementing jobs in ways that are 'typical' for each setting
- using intentional strategies to enhance social integration
- supporting self-employment
- post or follow-up support
- ensuring that people with severe disabilities can access supported employment
- quality outcomes result when services adopt a principles- and values-led approach to supported employment<sup>357</sup> (*Recommendation 5.1.11*).

Additional strategies recommended for use by supported employment services are:

- careful vocational assessment and job matching
- use of case management and job coaching
- clear explanation of duties, responsibilities, expectations and rules ahead of time
- undertaking task analysis (breaking complex tasks down into small logical components) to develop written and/or pictorial prompts and instructions
- arranging for or providing intensive one-to-one instruction and repetition of new job tasks
- supporting the person with ASD when deciding whether to disclose their diagnosis in the workplace
- helping employers consider the advantages of having an employee with ASD (eg, punctual, pays attention to detail, gains satisfaction from repetitive work; loyalty, stability)
- educating employers and co-workers about ASD
- supporting the person with ASD at times of employment stress (eg, organisational change, performance reviews)
- support in managing behavioural or emotional problems that could hamper work performance or relationships with management or co-workers
- recognising the risk to the person with ASD of discrimination, workplace intimidation and bullying, and taking appropriate steps to prevent and minimise this
- ensuring that the person with ASD knows their employment rights, is a competent self-advocate and/or has access to advocacy services<sup>47 270 370–372</sup> (*Recommendation 5.1.11, Recommendation 5.1.13a*).

Even people with severe autism or co-morbid intellectual disability can become engaged in meaningful work.<sup>354 372 373 380</sup>

Specialist schemes for assisting less able people with ASD to get into work have recorded success.<sup>373 375 376</sup> For many people with an intellectual disability, real work in real employment settings is preferable by far to vocational and day services<sup>358</sup> (*Recommendation 5.1.8*).

Features of ASD may both help and hinder finding work and obtaining employment success. For example, attention to detail may be valued highly, but may seriously hinder speed of output. ASD characteristics relevant to employment include:

- punctuality
- conscientiousness
- loyalty
- attention to detail
- perfectionism
- independence
- enjoyment of routine or repetitive tasks
- careful attention to the order and appearance of the personal work area
- strong preference for structured time, and discomfort with lack of structure
- unique work routines
- preference for no distractions or interruptions
- stress reactions to multitasking, change of priorities, conflict of priorities and deadlines
- difficulties with teamwork and components of work involving social skills
- anxiety about performance
- reluctance to ask for help or support, or accept positions of authority and supervision
- low awareness of danger to self or others
- difficulty with starting projects, time management issues



- strong reactions to changes in persons, environment or work conditions
- motivational issues regarding tasks of no personal interest
- difficulty with writing and making reports<sup>270 355</sup> (*Recommendation 5.1.12*).

A strong finding in a survey of workplace supervisors of people with ASD successful in employment was that the supervisors believed that assistance from supported employment services had been crucial.<sup>381</sup> The key supervision strategies identified by those supervisors were:

- job modification
  - maintain a consistent schedule and job duties
  - keep the social demands of the job manageable and practicable
  - provide organisers to help structure and keep track of work
  - add activities to reduce or eliminate unstructured time
- supervision
  - be direct and specific when giving directions
  - verify that communications are correctly understood
  - assist the employee in learning social rules and interpreting social cues encountered on the job
  - explain and help the employees deal with changes on the job
- co-worker relationships and social interactions
  - encourage co-workers to initiate interactions
  - ensure that one or two co-workers play a role in helping to give job-related suggestions and ‘keep an eye out’ for the employee
- support services
  - provide a sense of familiarity and reassurance until the employee and

company staff get to know one another

- transfer relationships and supports to company employees
- check in and remain on-call in case problems arise
- maintain a liaison role for non-work issues that affect the job (*Recommendation 5.1.13*).

Research on supported employment was updated as part of the living guideline process, and is summarised in Appendix 10.3, and available as full text from the Ministry of Health website.<sup>14</sup>

No literature was accessed on self-employment options for people with ASD. Self-employment may be an appropriate option for some people with ASD (*Good Practice Point 5.1.15*) and more research on this is required (*Good Practice Point 5.1.16*).

### Vocational services

All people with ASD should have the opportunity to participate in further or post-compulsory education and work (paid or unpaid). However formal education or work may not be the goal of every person with ASD, especially people with significant co-morbid conditions. For those people, access to meaningful daytime activities may be very important (*Recommendation 5.1.14*). In addition to recreation and leisure options (*see next section*), some people may want vocational services, or they may be obliged to use such services, because of a lack of educational and work options in their areas. Opinions on vocational services are varied, but many people with an intellectual disability report such services to be unfulfilling.<sup>358</sup> Vocational services for people with ASD must be of high standard. For further information on this area, the reader is referred to relevant sections of current New Zealand policy on people with disabilities.<sup>167 358 359 379</sup>

## 5.2 Recreation and leisure

### Summary of recommendations

Recommendations:		Grade
5.2.1	All children and adults with ASD should have access to leisure facilities and meaningful activity tailored to their needs and interests and designed to promote social inclusion.	B
5.2.2	Family members and whānau should be supported to maintain social relationships.	C
5.2.3	Leisure and recreation planning should be included in a student's/young person's transition programme and this information shared with post-school providers. Person-centred planning should: <ul style="list-style-type: none"> <li>• focus on individual choice and preference, including strengths, capacities, interests and experiences</li> <li>• include recognition that people with ASD have a right to privacy and a right to be autistic.</li> </ul>	C  B  C
5.2.4	Individual leisure plans need to be regularly evaluated in all services by staff clearly identified to have the responsibility and who should have received specialist education for the role.	C
5.2.5	All children with ASD should have access to good-quality play opportunities, including one-to-one support and adapted toys and equipment.	C
5.2.6	Where a child or young person is provided with a respite service or is outside the normal home environment, the environment needs to be structured and predictable, and it needs to support the function of the child in communication, personal independence and safe leisure skills.	B
5.2.7	Ongoing one-to-one support should be provided to those who need it to enhance their ability to pursue leisure pursuits.	C
5.2.8	Services should provide ongoing support where required to help someone with ASD build up and maintain social contacts, using strategies to promote social inclusion (section 3.2.b).	C



Recreation is a powerful tool for promoting independent functioning, community inclusion, education, employment, proficiency of life skills and improved overall quality of life. Meaningful routines, use of resources, recreation initiation and planning for structure and organisation are important processes for supporting a person with ASD to participate and enjoy a balance of leisure, work, self-care and other commitments<sup>382</sup> (*Recommendation 5.2.1*).

The Department of Recreation and Leisure, University of North Carolina, Chapel Hill, and the Department of Psychiatry from Division TEACCH (two nationally recognised programmes in the United States) collaborated on Project Autism, to conduct a three-year project which identified the support required to address recreation and leisure needs of people with ASD.<sup>382</sup> The project found that participating in recreation can help people with ASD to:

- expand their interests
- develop/improve their communication skills
- explore or expand their knowledge
- improve their cognitive functioning
- be with, interact with, and build friendships with others
- make leisure choices
- help others, and be able to contribute to home and community, including volunteering and opportunities to provide for others
- enhance self-control
- follow rules, directions and procedures
- gain others' respect
- enjoy completing and mastering things
- improve their physical functioning
- keep in shape physically
- relax physically and emotionally
- learn and improve coping skills
- heighten self-awareness and self-esteem
- promote community integration
- increase their life and leisure satisfaction.

Project Autism also identified a number of sources of information as useful for completing an assessment to identify the support that people with ASD will need to make leisure and recreation choices. These sources included:

- verbal self-reporting
- information gathered from a variety of sources, including everyone who interacts with the person
- observation.

Project Autism produced a manual, which included a section describing the steps and processes to help an individual with ASD become involved in a recreation activity of choice. These steps included:

- personal strengths
- goals and wishes
- approaches to learning – where a child or young person has communication difficulties, using concrete items such as pictures or photos, choice boards, social stories and observation of the individual can identify leisure interests and provide a means of evaluating satisfaction
- leisure interests and satisfaction to support future planning – use of vocabulary with which the individual is familiar; evaluation of the level of satisfaction of the individual
- meaningful routines including a balance of leisure, work, self-care and other commitments
- use of resources found in the home and wider community
- identifying who is responsible for recreation initiation and planning.

### 5.2.a Barriers to participation in leisure and recreation pursuits

People with disabilities who do not take part in sport and leisure activities may become isolated, lonely and miss out on activities which are fun and which provide opportunities to make friends and learn new skills.<sup>383</sup>

Findings from three separate studies have identified a number of common barriers preventing participation in family and community activities, and these studies have informed both the New Zealand and United Kingdom governments' strategies for promoting social inclusion for people with an intellectual disability.<sup>383–385</sup> The studies reported that key barriers preventing participation include:

- negative attitudes and a disabling environment
- poverty, reliance on benefits or low income versus the cost of some leisure pursuits
- the need for support to prepare for activities and to participate in activities outside the home
- lack of energy, exacerbated by the emotional and cognitive energy expended on preparation, transport and disability-specific issues
- the extra time used for ordinary living due to the effects of the disability
- difficulties of communicating and expressing choices
- community groups involving people with disabilities may be more likely to include people with physical or sensory disabilities than those who have intellectual disability
- community attitudes that can make people's experiences in the community frightening and unpleasant.

Tony Attwood, an internationally recognised expert in ASD, described at the Autism New Zealand Conference 2004 how having an ASD can affect an individual's ability to participate in their community.<sup>386</sup> In his presentation, he explained how the special interests of people with ASD can dominate a person's time to a point where the interest can:

- become obsessive-compulsive
- become obtrusive for the family
- cost money, with consequences for financial planning disproportionate to income and sometimes lead to criminal behaviour in order to access a special interest.

However, special interests also provided positive functions for the person with ASD and can:

- provide enjoyment
- reduce anxiety
- motivate and support learning
- become a source of income and employment
- be a means of making friends.

### 5.2.b Strategies to promote community participation

A study that investigated peer relationships and participation in social and recreational activities of 235 adolescents and adults with ASD who lived at home found that, consistent with previous research, prevalence of friendships, peer relationships and participation in social and recreational activities were low.<sup>387</sup> Greater participation was predicted by:

- greater functional independence
- less impaired social interaction skills
- higher internalising behaviours

- environmental support from maternal participation in social and recreational activities
- greater number of services received
- inclusion in integrated settings and community based services.

A study of a social contact group set up for four men with learning difficulties<sup>388</sup> reported that, for people with severe learning disabilities, the most important factor in developing friendships was the physical opportunity they had to meet others in a supportive environment. It was not how socially adept they were, nor was it the severity of their learning disability.

Access to leisure facilities and meaningful activity tailored to needs and interests should be designed to promote social inclusion and, where appropriate, should involve family, whānau and friends. Supporting the family to maintain social relationships may be beneficial for the individual with ASD<sup>387</sup>

*Recommendation 5.2.2*). The family's goals and interests related to leisure time will also need to be considered, including shared activities, independent activities and timing of activities.

Personal and community safety issues need to be addressed to ensure community participation is enjoyable. Skills can be taught or enhanced through recreation opportunities (eg, appropriate touching, crossing the street, using money and waiting in line). Control and choice are at the core of self-determination and should be the principles on which any recreation or leisure involvement is based. A person's strengths should therefore be taken into account to ensure that he or she has a sense of control and choice.<sup>389</sup>

Two independent reviews of literature and health and disability services for people with intellectual disability in New Zealand have identified a number of strategies to

promote community participation.<sup>167 384</sup>

These include:

- person-centred planning with a focus on individual abilities, including strengths, capacities, interests and experiences, and respecting the choices and preferences of the person concerned (*Recommendation 5.2.3*)
- working with local neighbourhoods and communities to promote participation in and planning for integrated activities
- working to change communities to ensure they become less prejudiced and more inclusive of people with ASD
- identifying and using natural (unpaid) supports
- providing formal support
- using visual supports (eg, social calendars to promote choice and preferences)
- developing individual leisure plans that are regularly evaluated (*Recommendation 5.2.4*)
- identifying services and staff with responsibility for leisure plans, and ensuring they have appropriate education and resources (*Recommendation 5.2.4*)
- ensuring that policy and service design address barriers to leisure.

In New Zealand, the Halberg Trust links people with disability to sport and active leisure, as do disability not-for-profit community groups. Information about recreational programmes in the community can be accessed through the Needs Assessment and Service Coordination (NASC) agency, the Citizens Advice Bureau, Autism New Zealand and Disability Information Advisory Services.

### 5.2.c Children with ASD

Difficulty in understanding and following social situations and cues can cause problems during interactions for people with ASD. Problems with self-initiation, motor planning and sequencing, plus a restricted repertoire of interests and play activities, mean that many children with ASD have difficulty developing play skills that enable them to occupy themselves productively. Play can be one of the most difficult times for children with ASD: it is less structured and harder to understand because of the many social aspects to follow and involves initiation and follow-through.<sup>382</sup>

Many children with ASD need to be taught play skills that can provide the basis for more complex social play later on. All children with ASD should have access to good-quality play opportunities, including one-to-one support and adapted toys and equipment (*Recommendation 5.2.5*). Consideration of the environment and the context in which new skills are to be taught is important, because some children with ASD experience difficulty transferring skills to different settings. For example, planning and communication between families and carers is important, where children and young people are provided with a respite service. Any environment needs to be structured, predictable and support the function of the child in communication, personal independence and safe leisure skills<sup>382</sup> (*Recommendation 5.2.6*).

A child with ASD is likely to need help to explore recreation options. Children with ASD often display initial resistance to try a new experience, which could be driven by dislike of new or novel situations, or resistance to change. All children develop new interests and have preferences, and children with ASD can have strong and unusual interests. Determining whether these interests are appropriate needs careful consideration. The challenge is to

explore all opportunities while maintaining structure, keeping the child safe and in good health, and maintaining the right balance of activities.<sup>31</sup> Jen Birch, a New Zealander who provides personal insight into her life as an adult diagnosed with ASD, suggests careful monitoring of the amount of recreational activity in which an individual participates and providing an adequate balance in learning, recreation and special interests.<sup>172</sup>

### 5.2.d Young people with ASD

Young people with ASD often have particular difficulties with social interaction and reciprocity. The severity of social impairment and practical language problems varies greatly within the ASD population, with observable behaviours including high levels of anxiety, obsessional disorders, depression, suicidal ideation, rage and defiance.<sup>297 390 391</sup>

Adolescence marks the transition from childhood to adulthood, with the accompanying pressure to conform. Typical characteristics noted in adolescents with ASD are:

- poor communication skills
- excellent vocabulary
- intense interests and pursuits (usually isolative) that can seem obsessive
- a tendency to prefer predictable events, resulting in problems of social flexibility
- problems in self-organisation and productivity, especially around school work
- a preference and overt wish to engage in self-interest activities.

There is general consensus from experts in ASD internationally about the support strategies and services that can assist young people with ASD.<sup>47 297 390 392</sup>

Young people with ASD can be supported through:

- social therapy and social skills groups
- one-to-one support for acquiring social skills, time to achieve these skills and a safe place for practice
- being taught friendship skills
- adults acting as guides and coaches, facilitating relationships and providing opportunities to interact with peers
- life-skills training
- opportunities for supervised high-interest activities often enjoyed by people with ASD (chess clubs, computer clubs, animal husbandry, writing classes, music appreciation, etc)
- alternatives to unstructured social situations
- availability of safe adults who can be accessed in times of crisis
- specialised staff
- if required by an individual, ongoing support to help build and maintain social contacts.

Individual support is sometimes needed to link the person into existing community activities, interests, clubs and leisure facilities and also to help them identify social networks (*Recommendation 5.2.7*). Some New Zealand schools have included leisure and recreation planning in a student's transition programme. It is important that information in a student's transition plan is shared with post-school providers<sup>47</sup> (*Recommendation 5.2.3*).

### 5.2.e Adults with ASD

Leisure activities can be an important source of empowerment, self-expression and community participation for adults. For full community participation, social relationships and networks are of critical importance<sup>384</sup> (*Recommendation 5.2.8*).

People with ASD can have strong and sometimes unusual interests and incorporating these into a leisure plan is an important issue to address. Interests can be expanded to include those that are more socially acceptable and this can offer additional opportunities for skill development and social interaction. A survey has identified the following functions of special interests in the lives of people with Asperger syndrome:<sup>386</sup>

- genuine enjoyment
- security
- comfort and relaxation
- facilitation or avoidance of social interaction and a means of reducing anxiety.

New experiences and new activities can feel very threatening for people with ASD, and adequate and sensitive support is required when beginning new, unfamiliar activities.<sup>172</sup> Support is needed to help a person with ASD choose one or more sporting and recreational activities and learn the skills necessary to participate.<sup>382</sup>

An increasing emphasis is being placed on sport as a recreation choice.<sup>190</sup> While there are people with ASD who enjoy team sports, personal accounts and observations from individuals with ASD and from parents note that these activities require many social skills, and that team activities need to be chosen carefully.<sup>172 393</sup>

For adults, including people with disabilities, work is viewed as the path to social and economic integration. As participation in paid employment becomes more common for all New Zealanders, increasing concern about how to achieve a work-life balance has been raised, including the role of the New Zealand Government and general public and communities in helping people overcome the barriers that prevent a balanced lifestyle.<sup>394</sup>

The New Zealand Department of Labour completed a project in 2004 to develop policies and practices to promote better balance between paid work and life outside work. Research of articles and projects, and consultation which included 700 responses from individuals and organisations, identified mobility issues as obstacles for some people with disabilities and a range of problems for parents of children with disabilities.<sup>394</sup>

Barriers to a balanced lifestyle for adults with ASD are exacerbated by higher rates of unemployment than among other citizens and barriers presented by a person's ASD and special interests, which are often solitary.<sup>384 395</sup> An ASD viewpoint should be considered when discussing lifestyle balance. Individuals and parents of children with ASD emphasised in personal correspondence and in literature that, while following personal interests does not necessarily have to isolate a person, people with ASD do have a right to privacy and a right to be autistic<sup>172 396</sup> (*Recommendation 5.2.3*).

### 5.3 Contact with the justice system

#### Summary of recommendations

Recommendations:		Grade
5.3.1	The victimisation of people with ASD should be further researched.	C
5.3.2	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
5.3.3	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
5.3.4	If people with ASD are abused, they should receive services from Child, Youth and Family (CYF), Victim Support, Accident Compensation Commission (ACC Sensitive Claims Unit) and other similar agencies.	C
5.3.5	Research is needed on the effect of abuse on people with ASD and how to reduce these effects.	C
5.3.6	Application for the appointment of a welfare guardian or property manager should be made to the Family Court in cases where there are serious concerns about the ability of a person with ASD to manage his or her financial/personal affairs and guard himself/herself against harm.	C
5.3.7	Further research is needed into the support needs of people with ASD who are complainants and witnesses in criminal cases, their reliability as witnesses, and the suitability of current provisions for vulnerable witnesses.	C
5.3.8	The prevalence of people with ASD in prison and secure settings needs further investigation.	C

Recommendations:		Grade
5.3.9	Research is needed into how to minimise the stress experienced by people with ASD when they come into contact with the police and criminal justice system.	C
5.3.10	Families and whānau, and carers of people with ASD should develop good relationships with their neighbours and (where appropriate) provide them with information on ASD, to ensure that neighbours understand them and deal with concerns informally wherever possible.	C
5.3.11	Families and whānau, carers and professionals should ensure that measures are undertaken during the childhood of the person with ASD to prevent the characteristics of ASD developing into behaviour that leads to victimisation or criminal offending.	C
5.3.12	Young people and adults with ASD should be taught their legal rights, and be prepared in advance with information should they ever have contact with the police and legal authorities. Appropriate resources and training should be developed to assist with this.	C
5.3.13	Families and whānau, and carers should be trained on how to support people with ASD who come into contact with the police.	C
5.3.14	When it is known or suspected that an adult with ASD who is charged with a criminal offence may have an intellectual disability, the suitability of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 is determined.	C
5.3.15	People with ASD involved in disputes within the Family Court are advised to seek assistance from solicitors and advocacy services with knowledge and experience in ASD.	C

Good Practice Point:	
5.3.16	People with ASD who are victims of crimes should access support from Child, Youth and Family (CYF), Victim Support, Accident Compensation Commission (ACC Sensitive Claims) and other similar agencies.





### 5.3.a People with ASD as victims of crimes

Although it is generally accepted that people with ASD and other disabilities have a higher likelihood of contact with the police, courts and criminal justice system than other people,<sup>397 398</sup> little research on this could be found. Certainly people with disabilities have an increased risk of being victims of crimes.<sup>398</sup> It is believed that people with ASD probably share certain vulnerabilities with other people with disabilities, which increase the likelihood that they will be victims of crimes (*Recommendation 5.3.1*).

For people with intellectual disabilities, some of these vulnerability factors are:

- misinterpretation of social cues
- difficulties recognising danger
- poor self-protection skills
- no or poor 'keeping safe' education
- acquiescing to behaviour they do not like in order to have a social contact
- dependency on others
- limited access to resources.<sup>398</sup>

Vulnerability to being a victim of crime may also be related to offender characteristics (eg, personality, occupation), characteristics of the interactions between offender and victim (eg, legitimate authority and power), social control, the environment in which the offence occurs and the culture of society (eg, attitudes towards people who are different).<sup>398</sup>

The first step in prevention is good-quality care, especially when people with ASD are young or also have an intellectual disability. Parents, families, whānau, teaching authorities and service managers/coordinators should try to ensure that anyone in regular contact with the person with ASD is considered to be

safe (ie, no relevant criminal convictions, not violent), is preferably trained in ASD, and is appropriately supported and supervised if they spend much time together with the person with ASD (*Recommendation 5.3.2*). As children with ASD grow older, social skills development is important; for example, education in sexual safety strategies, community safety, strategies to keep safe when out at night and what to do if they are abused<sup>399–401</sup> (*Recommendations 5.3.3, 5.3.4*).

Little research has been undertaken on the effects of abuse on people with disabilities or ASD, or how to reduce the effects of such stress.<sup>402</sup> Although a study<sup>402</sup> used a structured parental interview to delineate the effects of abuse from other behaviour in non-verbal children with autism who had been exposed to abuse, much more research is needed (*Recommendation 5.3.5*).

People with ASD need to be able to access the age-appropriate service for supporting people who are at risk or who have been victimised (eg, Child, Youth and Family (CYF), Victim Support, Accident Compensation Commission (ACC Sensitive Claims Unit) and other similar agencies) (*Good Practice Point 5.3 16*). In cases where people with ASD are unable to manage their property and personal welfare decisions and guard themselves against harm (eg, if they have a severe intellectual disability as well), the Family Court, on application, may appoint someone else to manage their affairs (*Recommendation 5.3.6*).



Special legal provisions and practices in New Zealand have been developed to manage situations in which people with intellectual disability are complainants and/or witnesses in criminal cases.<sup>403</sup> These practices are research based, and there is a growing international literature in this area.<sup>404 405</sup> While some of this will be of relevance to people with ASD who also have an intellectual disability, more ASD-specific research is needed as the issues may be different (*Recommendation 5.3.7*). For example, in contrast to non-autistic people, people with ASD may well be less likely to make 'false memory' errors when interviewed.<sup>406</sup> Furthermore, research is needed on how best to support people with ASD to give evidence. For example, while facilitated communication (FC) was used to assist non-verbal people with ASD to give evidence in some court settings internationally in the 1980s and 1990s, research suggests that the results of FC are not valid and that FC should not be used in court.<sup>407</sup>

### **5.3.b People with ASD suspected, accused, charged, convicted of crimes**

Despite some high-profile criminal cases where people with ASD have been convicted of serious crimes, no strong evidence exists associating ASD with criminal behaviour.<sup>270 360 408 409</sup> For example, in a study published in 1999, ASD was diagnosed in only 2.4% of the total population of patients in special hospitals in England.<sup>410</sup> However, the prevalence of ASD in the prisons and secure settings is unknown;<sup>270 411</sup> research is underway in Wales to explore this area further<sup>412</sup> (*Recommendation 5.3.8*).

It has been hypothesised that people with ASD may be at risk of committing offences because of ASD-related behavioural traits and characteristics, such as lack of empathy, lack of social understanding, pursuit of obsessional interests, failure to recognise the implications of their behaviour, rigid adherence to rules and misuse by others.<sup>270 360 413</sup> However an alternative view is that engaging in criminal acts is due to the affect of co-morbid conditions, such as attention deficit hyperactivity disorder, depression or poor anger management.<sup>414</sup> Rarely does there appear to be a deliberate intention on the part of people with ASD to hurt others.<sup>270 413</sup>

Contact with police, courts and the criminal justice system is anxiety provoking for most people, and people with ASD have particular support needs. Given the nature of ASD, young people and adults with ASD are likely to experience difficulties when in contact with the police, courts and criminal justice systems.<sup>270 397 415</sup> Furthermore, common practices in these systems may inadvertently victimise people with ASD (eg, confrontational interviewing, incarceration with violent offenders), exacerbate their anxiety, expose them to risk (ie, of physical harm, challenges to their interviewing style, charges of bias) and undermine legal and criminal justice processes (*Recommendation 5.3.9*).

Expert opinion on preventative measures regarding contact with police and criminal justice includes the following recommendations:

- consider giving neighbours information on the person with ASD (eg, name, physical appearance, likes and dislikes, basic routines, contact details, names and details of the person) so that they know who the person is and can develop a better understanding of his or her behaviour (*Recommendation 5.3.10*)

- develop good relationships with neighbours, so that concerns are dealt with informally wherever possible (*Recommendation 5.3.10*)
- intervene early on in the life of the person with ASD to ensure that the obsessional interests, social deficits and communication problems of childhood do not become entrenched behaviours that expose the person to risk of victimisation or criminally offending (*Recommendation 5.3.11*)
- establish firm and consistent rules in childhood, so that people with ASD will accept limits on their behaviour in adulthood<sup>270 397 399 400 416 417</sup> (*Recommendation 5.3.11*).

Advice for the person with ASD when having contact with the police is:

- do not run away or make sudden movements
- try to stay calm
- consider letting the police officer know that you have ASD or some of the symptoms (it may help to have an information card on ASD kept in your wallet or purse)
- ask for someone who you trust and can rely on to be contacted (carry the telephone numbers of trusted people with you at all times)
- if you are suspected of a crime, ask for a lawyer, and do not answer any questions until the lawyer is present
- remember that refusing to talk does not suggest guilt
- you do not need a lawyer with you if you are a victim or reporting a crime, but it may help to have an information card on ASD and a support person present<sup>399 415</sup> (*Recommendation 5.3.12*).

Advice for the family and whānau and support people of young people and adults with ASD, when having contact with the police and courts, includes:

- have summary information on the person with ASD readily available, so that it can be given to the police, and any lawyers, at the start of the contact
- ensure that the legal rights of the person with ASD are upheld
- seek legal services if the person is suspected of or charged with a crime
- contact specialist advocacy services
- prepare the person with ASD well for pre-court and court appearances, especially regarding the conduct of the court<sup>47 399 418</sup> (*Recommendation 5.3.13*).

Police, courts and criminal justice personnel (eg, lawyers, probation officers, court staff, judges and prison officers) need to know:

- how to recognise when the person they are in contact with has ASD
- the implication of ASD on the behaviour of the person with ASD, and his/her likely responses to the behaviour of the police, court and criminal justice personnel<sup>397 416</sup>
- strategies to ensure that the legal rights of all people concerned are upheld, and that the appropriate legal processes can be followed (eg, using an expert witness in court; recognising that people with ASD and other developmental disabilities are vulnerable in formal interviewing conditions, whether as potential suspects or witnesses; the vulnerability of people with ASD when held in custody)<sup>270 403 405</sup>
- the potential impact of minimising the seriousness of the inappropriate behaviour of a child or young person with ASD, including the potentially reinforcing effects of police being ‘too

nice', giving cups of tea and taking people for rides in the police car.<sup>270</sup>

The recommendations that ASD professionals and services develop good working relationships with police, courts and criminal justice facilities, provide appropriate education and keep lists of solicitors and advocacy agencies with expertise in ASD may well be appropriate for New Zealand<sup>47</sup> (*Recommendation 6.15*).

The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 provides New Zealand courts with alternative options for managing situations where people with an intellectual disability are charged with committing an imprisonable offence. These include specialist risk assessments, alternative sentencing options and directing services to provide appropriate interventions. The cases of young people and adults with ASD who are charged with an imprisonable offence, and who are also suspected or known to have an intellectual disability, may be more appropriately managed under this legislation (*Recommendation 5.3.14*).

### **5.3.c The Family Court**

People with ASD may well find themselves in contact with the Family Court if their marriage or life partnership breaks down and if the custody and access of their children is under dispute. No information on this was available at the time of developing this guideline. However, because of the characteristics of ASD, there is a risk of significant issues in this arena, and people with ASD are advised to seek legal advice from solicitors and advocacy services experienced and knowledgeable in ASD (*Recommendation 5.3.15*).



## Part 6

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### Professional learning and development

“People who know the details of 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.”

## Part 6 Professional learning and development

### Summary of recommendations

The following recommendations have been drawn from throughout the guideline. They have been grouped according to the aspect of professional learning and development which they address. Readers should refer to the cross-referencing for more information.

Recommendations:	Grade	Cross-reference
<b>Education for assessment and diagnosis</b>		
6.1 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	1.1 Identification and diagnosis
6.2 Professionals administering standardised ASD assessment tools should be provided with appropriate training. When reporting the results of ASD-specific tests, caution should be exercised as New Zealand norms have not yet been established.	C	1.2 Assessment Appendix 10.5
6.3 Norms should be developed for ASD assessment tools specifically for the New Zealand population.	C	1.2 Assessment Appendix 10.5
<b>Education for planning and implementing services</b>		
6.4 Professional learning and development 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	2.1 Relationships
6.5 Social service staff members should have adequate education in child-welfare issues relating to parents who have ASD.	C	2.1 Relationships
6.6 Speech-language therapists should have access to education in scaffolding adult learning.	C	3.2.a Communication and literacy skills
6.7 Professional learning and development for teachers and other professionals should have a specialised component which includes developing positive attitudes and expectations.	C	6 Professional learning and development
6.8 Parents, families and whānau, and staff who support people with ASD should be provided with education on their health needs and how to support them when interacting with medical and health care practitioners and services.	C	2.3 Physical wellbeing

Recommendations:		Grade	Cross-reference
6.9	Professional learning and development in functional assessment and positive behaviour support should be available to parents or carers, teachers, school staff and specialists.	A	3.2.e Self management skills and addressing challenging behaviour
6.10	School staff should receive professional learning and development in modifying the learning, physical and social environments to support the child.	C	3.2.e Self management skills and addressing challenging behaviour
6.11	Teacher aides, education support workers (ESW) and other paraprofessionals require professional learning and development for working with specific children and adults.	C	6 Professional learning and development
6.12	Guidelines for the roles and responsibilities of paraprofessionals and for their supervision should be developed.	C	6 Professional learning and development
6.13	Professional education about the difficulties faced by young people with ASD and ways to minimise these should be a priority for professionals who work in secondary schools.	C	3.3 Particular issues for secondary students
6.14	Professionals who design and implement behavioural interventions should be appropriately qualified and experienced.	C	4.3 Psychological approaches to the management of ASD
6.15	Police, court staff, solicitors, lawyers and criminal justice personnel should receive relevant education on ASD, provided by an appropriate educational organisation.	C	5.3 Contact with the justice system
Quality of education and services			
6.16	Professional learning and development should be consistent with the evidence and principles of quality provision.	B	6 Professional learning and development
6.17	Agencies should ensure that members of staff have current (and ongoing) good quality education in ASD and that their agency procedures incorporate best practice in ASD.	C	4.2 Problem minimisation and avoidance

Recommendations:		Grade	Cross-reference
6.18	Education and interventions should be planned and implemented by professionals* with appropriate ASD education and qualifications.  <i>* In New Zealand, these are professionals who meet the Ministry of Education's criteria to provide services in early intervention and services in other educational settings.</i>	C	3.1 Approaches to teaching and learning in the early years
6.19	Professionals (including teachers) who are responsible for students with ASD need release for professional learning and development, consultation, family meetings, observation, mentoring, planning and supervision.	C	6 Professional learning and development
6.20	Different professional groups and multidisciplinary teams should be given the opportunity to train together.	C	6 Professional learning and development
6.21	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	6 Professional learning and development
6.22	Distance learning opportunities should be developed for those working away from the main centres.	C	6 Professional learning and development
6.23	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	6 Professional learning and development
Other recommendations			
6.24	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.	B	6 Professional learning and development



Good Practice Points:			
6.25	Support and training should be provided to education professionals to develop peer-mediated strategies for social development.	✓	3.2.b Social development
6.26	Consumers should investigate the post-qualification training and areas of specialisation of the health care professionals that they are approaching for diagnostic assessment and consider seeking recommendations from within the ASD community.	✓	1.2 Assessment
6.27	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.	✓	6 Professional learning and development
6.28	A full review of the professional learning and development literature relating to all sectors should be undertaken.	✓	6 Professional learning and development

## 6.1 Personnel

The following groups from the different service sectors were identified as those who should have access to professional learning and development. The educational needs will vary with some requiring a very high level of knowledge and skill, for example, developmental paediatricians, speech-language therapists and psychologists. Some may require good skills and knowledge, for example, general paediatricians, teachers and paid care providers. Others may have their needs met through education in awareness and positive attitudes, and knowledge of sources for further advice when needed, for example, general practitioners, radiographers, court staff and school board of trustee members.

### Health, human services and education professionals who require access to knowledge and skills in working with people with ASD

#### Health

- Medical:
  - General practitioners
  - Paediatricians
  - Psychiatrists: child and adolescent; adult
  - Internal medicine specialists (or physicians)
  - All specialties
- Dental:
  - Generic
  - Specialist (eg, oral health disability service at Green Lane)
  - Dental therapists
- Psychologists:
  - Clinical psychologist
  - Other psychologists (educational or organisational)

- Behaviour support specialists
- Applied behaviour analysts
- Counsellors
- Mental health staff
- Physiotherapists
- Occupational therapists
- Speech-language therapists
- Social workers
- Orthotists
- Nurses – general
- Plunket nurses and others doing Well Child assessments
- Radiographers
- Radiation therapists

#### Human services

- Mental health court liaison (social workers/nurses)
- Other staff in the health services who work with people with ASD
- Needs assessors
- Service coordinators
- Care managers
- Compulsory care coordinators
- Court staff (including solicitors)
- Forensic services staff
- Police
- Holiday programme workers
- Voluntary workforce – non-regulated
- Recreation service staff
- Care and residential service providers, for example, residential services, contracted respite services (including Ministry of Health-contracted providers and those subcontracted by service providers)
- Disability support workers

- Other support workers
- ASD Disability Information Advisory Service (DIAS) providers
- Regional Intellectual Disability Care Agency (RIDCA) staff, including paraprofessional support workers in Regional Intellectual Disability Supported Accommodation Services (RIDSAS)
- Taxi drivers, mobility drivers
- Government departments especially:
  - Work and Income
  - Child, Youth and Family
  - ACC
  - Justice

#### **Education services**

- Teachers (early childhood, primary, intermediate, secondary)
- Teacher aides and support workers such as for education, communication and behaviour
- Principals
- Boards of trustees
- Librarians
- School counsellors
- Psychologists working in education
- Occupational therapists working in education
- Speech-language therapists working in education
- Physiotherapists
- Specialist teachers (early intervention teachers, special education advisors, Ongoing and Reviewable Resourcing Schemes (ORRS) funded specialist teachers, Supplementary Learning Support teachers)
- Special education facilitators

- Tertiary organisations – disability support staff
- Lecturers who have students with ASD enrolled in their courses
- Others who interact with students in the course of their work, for example, taxi drivers, bus drivers, school cleaners and maintenance people etc

#### **Education for health personnel**

Education for health personnel in understanding and working with people with ASD should occur at the following stages:

- Pre-service training/undergraduate training
- Postgraduate/specialty training
- Continuing Professional Development/ Continuing Professional Education/ Continuing Medical Education
  - Generic – all
  - Specialist

The competencies at each of these levels should be defined (*see section 2.3: Physical wellbeing*).

## 6.2 Some principles of effective professional learning and development

The resources and scope of the current guideline did not allow for a comprehensive search on all aspects of professional learning and development. However there are many recommendations throughout the ASD Guideline which relate to the need for professional education. A strong theme has emerged from the evidence surveyed by all workstreams. Parents, specialists, education, health and other human service professionals and paraprofessionals who work or live with people with ASD can improve the outcomes for those individuals if they have the necessary skills developed through appropriate education.<sup>11 104 197 211 419</sup>

Some general principles for professional learning and development have been developed. It is the opinion of the workstreams that these are applicable to all professionals, paraprofessionals and other people who provide support to people with ASD.

While only a small amount of research was identified about the most effective personnel preparation, there is agreement that it is important to translate research about effective practice into information that practitioners can use.<sup>104</sup> There is a need for all groups to receive professional education which is up to date and ongoing.

**1. To be effective, participants need opportunities for meaningful instruction and opportunities to observe and practise new skills while receiving coaching, mentoring and feedback.**<sup>104 209 419</sup>

There are many models for professional in-service development. Much of the professional learning and development currently offered takes place in 1- to 2-day sessions that are topic-specific and are facilitated by an expert in an area such as communication.

While expert speakers may address important information and the expertise may be motivational, these opportunities do not necessarily provide participants with the comprehensive skills needed, or relate to mastery of new skills. This learning needs to be supplemented by practice, coaching, mentoring and feedback for confident application of new skills.

**2. No one professional learning and development course or method will meet the needs of any group and professional learning and development opportunities need to be ongoing and offered in a variety of ways.**<sup>11 419</sup>

Professional learning and development methods commonly used include:

- in-service programmes
- tertiary courses
- seminars with follow-up visits for on-site coaching and mentoring teachers with the provision of support via email
- distance learning programmes (university distance teaching, video- and telephone-conferencing, online)
- general information short workshops
- itinerant trainers and consultants for small group or individual instruction, coaching and mentoring

- access to resource and technical assistance centres, which can provide professional learning and development, training manuals, training videos and CD-ROMs
- individual professional upskilling and reflection, including self-monitoring and peer review.

All these modes have different strengths and are appropriate to meet the wide range of needs. In particular, distance learning needs to be supported and developed for professionals working away from the main centres.<sup>11</sup>

### **3. Professional learning and development needs to be in ‘quality time’, not in ‘twilight time’.**

Professionals should be released to participate in learning opportunities. They should also be provided with time for planning, to practise new skills, receive feedback and coaching and to problem solve and communicate with other team members.<sup>11 211</sup>

### **4. Professional learning and development with a focus on ASD should take place both during initial training and continue to be available throughout the working life of the professional**

ASD awareness and basic general skills will ideally be incorporated into the pre-service education of all relevant groups. For staff who will have regular contact with the person with ASD, there should be intensive professional learning and development in the first 4 to 6 weeks of a child or adult’s placement or appearance on a case list. Ongoing mentoring should be available for the first year.<sup>104</sup> Education should be provided proactively and not wait until a problem develops.<sup>419</sup>

Parents also require access to information, support and education as soon as a concern about their child is identified<sup>11 419</sup> (see *section 2.2: Parent information and education*).

### **5. Professional education and learning at any level, including initial training, needs to include information and learning that affects the attitudes of participants.**

Positive teacher attitudes are determinants of success for students with disabilities in general education classrooms.<sup>211</sup> One study has reported that, with support and education, 86% of teachers were willing to accept a student with a disability, but less than 33% were prepared to do so without support and education. Access to appropriate support is a key factor in creating positive attitudes.<sup>211</sup> It is important to remember that the voice of the person with ASD and his or her family is an essential part of any professional learning and development.<sup>11</sup> It is likely that these factors are also true for other groups who work with people with ASD.

### **6. Professional learning and development should be offered at different levels to meet the needs of the following roles.**

This education will range from awareness-raising for the community at large to postgraduate level university courses.

#### **Parents**

Parents require education in many of the same skills as teachers and other service providers if there is to be consistency across settings. They need to be educated in the best practices in teaching and in reducing problem behaviours. They require opportunities for receiving modelling, coaching and feedback. Siblings can also benefit from some knowledge in these areas. Parent education will need to include individualised problem solving, including

in-home education or observation<sup>419</sup>  
(*further information and recommendations are found in section 2.2 Parent information and education*).

#### Frontline professionals

Professional learning and development and support should be available to any frontline worker such as educators, health professionals and paid carers who are responsible for a person with ASD.<sup>11 104 209 419</sup> Teachers require instructional strategies beyond the knowledge of general teacher education. It has been shown that the extent of teacher professional learning and development has a significant impact on teaching success, and that even teachers with special education or early intervention qualifications benefit from attending ASD-specific programmes of study.<sup>104 197</sup>

The content of professional learning and development programmes for all frontline service providers should include:

- knowledge of the disorder and the signs of ASD at various ages (*see Part 1: Diagnosis and initial assessment of ASD*)
- skills in interacting and communicating with people with ASD and their families and whānau
- the voice of the consumer (first-hand experience of ASD)
- parent involvement (family/whānau views and values)
- theoretical underpinning of instructional approaches
- the development of skill in a variety of techniques and natural teaching strategies
- the development of language and communication
- the development of social competencies

- the development of adaptive skills and supporting transitions
- providing structure
- trial teaching
- decreasing problem behaviours
- skills in supervision and management of paraprofessionals, organisation and collaboration with other team members.<sup>11 104 419</sup>

#### Paraprofessionals

Teacher aides, education support workers (ESW) and other paraprofessionals require professional learning and development for working with specific children and adults.

They need to understand:

- the individual's characteristics
- the individual's communication skills and style
- behaviour management techniques for this particular person
- instructional methods for the development of new skills
- optimum arrangement of the environment.

Every adult working with a person with ASD needs to develop the skills to deal positively with behaviour challenges. The paraprofessional should be able to use, with ease, all learning systems employed with the person (eg, Picture Exchange Communication System (PECS) or Incidental Teaching).<sup>211 420</sup>

Paraprofessionals and in-home carers need to be trained in strategies such as naturalistic teaching, visual supports, communication and social skill methods, as required.<sup>419</sup> A New Zealand study showed the importance of teacher aides understanding the usefulness of taking a facilitative role to assist interactions with peers rather than a role which tried to compensate for the child's difficulties and

do tasks for them. They reported that the teacher aides appeared confused about whether their role was a teaching or caretaking one.<sup>421</sup>

Guidelines for the roles and responsibilities of paraprofessionals need to be developed so that everyone has a shared understanding of the paraprofessional's responsibilities and role and who will provide supervision.<sup>104</sup> It is not appropriate for paraprofessionals to have sole responsibility for implementing or decision-making about interventions or programmes.<sup>211</sup>

#### Teams

Because students with ASD benefit from a high degree of structure and consistency, it is important that the team working around the child or person is coordinated and well informed and shares common information about specialised instructional and behaviour management strategies.<sup>104 211</sup> It is helpful if the team approach is reflected in the style of the professional learning and development and that different professions are given the opportunity to share learning opportunities.<sup>104</sup> It may also be helpful for parents to join with other workers in professional learning and development so that there is an opportunity for each to understand the others' issues and knowledge.

#### Specialists

It is recognised as important for all staff and parents directly involved in teaching and caring for people with ASD to have access to adequate support from specialists.<sup>11 104 211</sup> Staff who operate in a specialist role or who train others will need additional education.<sup>117 197 211</sup> The skills of those who provide education and support to others should be considered as the first priority in a national professional learning and development plan.<sup>11 104</sup>

As well as education in their professional area, specialists such as therapists, psychologists, specialist teachers and relevant medical consultants need advanced ASD-specific professional learning and development. They also require access to information networks and ASD-specific consultancy services. Professional learning and development in cultural awareness is particularly important.

Frontline staff require an opportunity to participate in hands-on education and ongoing mentoring, peer review and supervision from specialist staff.<sup>104 117</sup> Such specialist professionals need to understand a variety of approaches and techniques and be able to communicate with and educate other staff.<sup>104 419</sup> Ongoing professional learning and development should also take place through case reviews, reflection, reading and discussion of literature and supervision.

Many specialist professionals have been trained to work with children, or to provide a direct service. To provide parent education and professional learning and development for other professionals, specialists need to understand the core constructs of adult learning and techniques for teaching parents and other adults. Many specialists will also benefit from professional learning and development in supporting and developing teams who are working around the person with ASD.<sup>117 197</sup>

#### Consultants

Identification and development of consultants from each profession who will be available to support specialists and provide second opinions should be a priority.<sup>11 104 419</sup> Nominated people should be available to provide consultancy and professional learning and development to specialist staff.<sup>11</sup> This may not involve face-to-face work with children and adults but these consultants may require extra

professional development in scaffolding adult learning, facilitating peer review, supervision and mentoring, and facilitation of professional networks. They also need skills in evaluating programmes and translating research into practice.<sup>104 419</sup>

#### **Awareness in other professional groups**

There are many other professionals who are not involved in direct services to people with ASD. On occasion, these professionals may be required to interact directly with people with ASD in the course of their work. This may include professionals such as medical specialists, lawyers, those involved in the leisure industry and those providing community services such as librarians. These people need a level of awareness about the challenges which people with ASD face and knowledge of where to go to find further information and support, as they require it. Community education and awareness campaigns and information services should be developed and fostered.

### **6.3 Organisational structures to support professional learning and development**

The National Research Council lists the infrastructure supports required to develop an effective service for children with ASD. It is the opinion of the Guideline Development Team that the following aspects of the structure are relevant for all sectors which serve people with ASD in New Zealand:

- a national plan for personnel preparation around ASD across all sectors
- assistance for professionals in the form of support and ongoing professional learning and development
- development of tools for ASD programme evaluation
- development of a communication network for professionals working in the area of ASD
- development of demonstration programmes where professionals can observe and learn new skills
- development of a data system which would provide the information needed for the development of a plan for services and associated professional learning and development
- development of a national plan for services for ASD.

There is a need for professional learning and development to be coordinated nationally and for standards for professional learning and development to be developed.<sup>11 104</sup>



## Part 7

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### Māori perspectives

“You can experience anger and grief when your child is diagnosed with autism. You need time for it to sink in – it can mean a loss, but at least you then know what the problem is and hopefully the whānau will swing in behind you. Understanding what’s going on for them, or as much as you can is the main thing. I guess it’s about education in a way.”

## Part 7 Māori perspectives

### Summary of recommendations

Good Practice Points:		
7.1	<p>Information packages in relevant and appropriate language about ASD in health, education and disability services should be developed. In plain and simple language, the packages could include the following:</p> <ul style="list-style-type: none"> <li>• current knowledge of ASD across the continuum</li> <li>• set of symptoms inventory across age groups</li> <li>• dual diagnosis and differential diagnosis information</li> <li>• availability of specific health, education, and disability services by region</li> <li>• funding avenues across health, education, and disability services</li> <li>• recommendations on harm and safety issues</li> <li>• helplines by region</li> <li>• respite care information</li> <li>• reliable ASD (international and national) internet sites information</li> <li>• pictorial information</li> <li>• multimedia resources (eg, video).</li> </ul>	✓
7.2	<p>ASD information in English and te reo Māori should be provided and distributed through Māori and mainstream providers of health, education and disability services. Other points of distribution could include:</p> <ul style="list-style-type: none"> <li>• iwi organisations, rūnanga, marae</li> <li>• urban Māori authorities</li> <li>• professional organisations across Māori health, education and disabilities fields</li> <li>• mainstream television screening Māori programmes (eg, Marae)</li> <li>• Māori television</li> <li>• radio</li> <li>• libraries</li> <li>• all ASD support groups and networks</li> <li>• police and law enforcement agencies</li> <li>• Mental Health Foundation website</li> <li>• road shows and workshops.</li> </ul>	✓
7.3	<p>The appointment of a kaiarahi (guide) should be considered. The kaiarahi would work in conjunction with, and be supported across, the health, education and disabilities sectors involved with ASD.</p>	✓

Good Practice Points:		
7.4	An ASD antidiscrimination and destigmatisation campaign should be developed.	✓
7.5	A programme of empirical research that would provide baseline information about Māori and ASD should be developed.	✓

This part of the ASD Guideline comprises two sections. The first section provides a description of the methodology used to identify evidence-based information relevant to Māori and ASD and details the results of a literature review. As will be seen, this review is extended, in part, to comment on the association between culture and ASD. The second section outlines the background of a number of hui held throughout New Zealand on the topic of ASD and then provides a descriptive summation of the information elicited from attendees to the hui. These hui provided the opportunity for Māori to contribute their own views and perspectives of ASD. The Good Practice Points listed at the beginning of this part of the ASD Guideline were developed from the findings of the literature review which largely corresponded with many of the issues raised during the hui.

In recognition of the dearth of information available that reports on Māori and ASD, the Ministries of Education and Health identified the need to canvass the wider literature and include a more focused and specific Māori input into this guideline. To further this objective, a Māori Advisory Group was formed in 2004. This group was composed of representatives from Māori health, education and disabilities. All representatives of the group possessed knowledge of ASD.

## 7.1 Literature review

### Methodology

A full and comprehensive literature search was undertaken. The specific objective of the literature search was to identify evidence-based information relevant, or directly pertaining, to Māori and ASD.

The scope of the literature search was constrained to peer-reviewed publications by accredited scholars and researchers. Both quantitative and qualitative research was sought. Search categories were identified and cross-referenced with main terms appearing in annotated bibliographies reporting on Māori health and disabilities information.

Salient differences between an international and New Zealand context were also taken note of in preparation of the search. For example, evident within, in particular, some of the American and British literature is the continued use of the descriptor 'race' or labels of colour (ie, black, white) to describe different ethnic groups. A search was conducted using the descriptor 'race', although it is acknowledged that the notion of 'race' itself has been scientifically discredited. No search was undertaken using the labels of colour. Search tips on Māori and evidence, recommended by the New Zealand Health Technology Assessment were also used.

Various combinations of the following terms were used to conduct the search:

- Māori
- ethnicity
- race
- minority
- indigenous
- New Zealand
- New Zealander

- aboriginal
- tangata whenua
- whānau
- culture
- autistic spectrum disorder
- autistic disorder
- autism
- Asperger(s)
- ASD
- infantile autism
- mental retardation.

International and national databases searched included the fields of health sciences, education, life sciences (social and behavioural), disabilities, multidisciplinary fields, and Māori health. Databases included, but were not limited to: Te Puna, Social Science Citations Index, MEDLINE, PsycINFO, OVID, Cochrane Database of Systematic Reviews, VOYAGER and Index New Zealand (INNZ) Online. E-journals specifically relevant to ASD were also searched for articles published from the year 2000 onwards using the key terms noted above. The Google search engine was also employed to identify websites addressing Māori health, mental health, and ASD (international and national sites) specifically, and these were also searched for evidence-based information.

Literature selected to be included in the review commented directly on cultural concerns relating to assessment, diagnostic and management issues involving ASD specifically. The broadening of the search objective to cultural concerns was necessary because currently there is no evidence-based information available that reports directly or indirectly on Māori and ASD. For the purposes of this part of the New Zealand ASD Guideline, evidence-based information has been defined as that which satisfies standard conventions of systematic search methodology and criteria

of evaluation. The review included limited international and national literature. The rationale for integrating the material was due to the dearth of literature available. With these caveats in mind, the review undertaken is best regarded as an initial exploratory examination.

## Results

Only one publication was sourced that directly pertains to Māori and ASD.<sup>116</sup> This report, commissioned by the Ministry of Education, involved a discourse analysis of interviews conducted with 19 families who had direct experience of caring for children and young people with ASD. The purpose of Bevan-Brown's study was to enable the family to tell their own stories regarding their experience of caring for Māori children with ASD.

A synopsis of the findings raised in this seminal report included the issue of delayed diagnosis, a limited understanding of ASD on the part of families and lack of support including financial resources being made available to such families. The need for helpful people to be identified early once a diagnosis of ASD had been received and, concomitantly, the need for better information to be made available to Māori families were also prominent in Bevan-Brown's publication. Participants in this study also recommended the provision of more culturally affirming professional processes being made available. It was suggested that these could be provided from the point of first diagnosis through to the subsequent management of children and young people with ASD.

To supplement Bevan-Brown's work an extended search of the international literature was also undertaken using alternative search terms. Only two papers were identified that were of interest to this chapter. Other papers sourced, but not included made reference to the discredited

notion of 'race' or were specific to select population groups of other nations. In addition, many papers were based on unsubstantiated assertion or referred to contextual factors inordinately different from those of New Zealand. For these reasons they were discounted as being able to inform this review on Māori and ASD in a credible way.

The first paper by Shek and colleagues involved the validation of a Chinese version of the PEP-R scale.<sup>422</sup> Their findings supported the cross-cultural validation of this tool, which is used to identify psychometric properties of ASD. They recommended that their study be replicated in the Western context applying the back iterative translation method to the Chinese version of the scale.

The second and more substantive paper prepared by Mandell and Novak provides a theoretical review of the limited material available concerning the role of culture to influence families' treatment decisions for children with ASD.<sup>423</sup> The main foci of the paper include developing a more informed understanding of how families interpret ASD symptoms and, as a consequence, how these interpretations shape beliefs about causes of ASD and influence treatment-seeking strategies of families. According to Mandell and Novak, however, there is only one small study known that has empirically investigated the role of culture to influence treatment decisions involving children with ASD. Importantly, within this paper a number of significant issues are raised. These issues, however, largely refer to what is not known about the association between ASD and culture rather than what is known with some empirical certainty.

The authors point out the problem of measuring the culture concept reliably. They also identify the absence of any empirical information commenting either on ethnic differences in specific symptoms of ASD or known divergence across cultures regarding the relationship between aetiological beliefs held about ASD by families and subsequent treatment decisions. Whether delays in treatment seeking or preference for alternative treatments correspond with specific cultures' lay beliefs about causation is not known relative to ASD. Of notable interest is that Mandell and Novak draw attention to the variance in the quality of interactions with the health care system experienced by ethnic minorities when compared with others. They posit that clinical biases may influence representation of ethnic minorities with ASD. This may arise because of differential attitudes being directed to members of these groups by professionals from first presentation of ASD symptoms through to choices of treatment and management of ASD.

Access issues are also commented on by Mandell and Novak. In this regard, they suggest that geographical location of families bears more influence on children with ASD symptoms coming to the attention of health authorities than other socio-demographic factors, including economic status. The caveat to the recommendations proffered by these authors is that it ought to be understood that the goal with respect to ASD is seldom to treat the disorder proper, but rather to address other problems associated with ASD. They recommend research be undertaken to unravel the hypothesised relationship between culture and ASD. In their view, such research would include: identifying whether any cultural differences exist in symptom presentation of ASD; how families interpret symptoms of ASD and respond relative to help-seeking and treatment preferences; and, the need to elicit more information on the quality of interactions being experienced between ethnic minorities and health and educational systems.

The correspondence between recommendations made by Bevan-Brown (2004) and Mandell and Novak (2005) should not be overlooked. The following section reports on a number of hui held nationwide that were undertaken on the subject of ASD and Māori. As is described, these hui were organised to extend the opportunity for Māori to contribute their views and perspectives about ASD.

## 7.2 National hui

This section reports on information gathered from five hui that were conducted throughout New Zealand during 2005. As a participatory method of gathering information, hui allow members of the community to voice their views and opinions on topics of mutual interest. Gathering information from hui is therefore seen as a complementary method to more conventional research methods as it actively encourages information sharing and exchange in a public forum.

Considering the main objective underpinning this guideline, and in lieu of empirical evidence that reports directly on Māori and ASD, an important caveat needs to be made about the information reported in this section. The information that follows represents subjective opinions and views regarding ASD expressed by attendees at the respective hui. These views are not generalisable beyond the contexts in which they were recorded. Therefore, the content of this section should not be regarded as a consensual characterisation of views held by Māori about ASD, and it should not be assumed that the content is representative of the Māori community more generally. With this caveat in mind, the information that follows presents a valuable insight into issues raised by Māori participants at the hui about ASD. It is anticipated that the content of this section will provide a significant foundation from which future research examining Māori and ASD will draw from and build on.

The hui were held in Auckland, Wellington, Christchurch, Whangarei and Hastings. Representatives from the Ministry of Health, the Ministry of Education and the Disability Directorate facilitated the meetings.

### Background information

Following advice from the Māori Advisory Group, work was undertaken to identify points within the guideline-in-progress where specific information or commentary from Māori was required. Under the key themes of assessment and diagnosis, education and support, and transition, a number of questions were developed. Along with these questions, background information about ASD was developed as supporting material.

To encourage further Māori input about both the questions and supporting material, a hui was held in April 2005 with whānau who had experience in providing support to people with ASD. The purpose of this hui was to seek responses to the information that had been developed and to improve and extend the existing materials where it was deemed necessary. The outcomes from this hui were summarised and the resulting information was then reviewed by the Māori Advisory Group. Using these materials, an inventory of structured questions was developed to serve as a guide to prompt discussion at five hui held during November 2005. An open-ended question was also included to allow for more candid discussion on issues otherwise not included under each of the key themes.

Questions included in the guide covered the following themes:

- factors influencing representation
- assessment and diagnosis
- post-diagnosis support
- the need for a kaiarahi
- education
- services and ongoing support
- information
- guideline development
- other ASD related issues – open discussion.

Invitations were extended to all interested individuals using a number of networks. The five hui were held in three cities and two large urban townships, namely: Auckland, Wellington, Christchurch, Whangarei and Hastings. About 150 individuals attended the hui. Participants included a wide range of professionals and laypersons. In attendance were representatives from health services, Ministry of Education, Special Education, Child, Youth, and Family, kaupapa Māori services, ASD support networks, and members from other interested groups including the lay public.

It is important to note that given the procedures undertaken to develop the key themes, the context in which the information was generated, and the Māori frame of reference to which this chapter refers, the methodological approach that is most closely aligned with this process is exploratory research. To maintain the integrity of participants' subjective views about ASD and limit the potential for interpretative biases, a descriptive analysis identifying the main issues raised was undertaken. The feedback from the hui was collated under the key themes and then organised into main categories matching those themes. A descriptive summation of the information is presented.

The following information is organised under eight major themes. Specific questions are posed under each of the key themes. Each of these themes and accompanying questions is briefly described and a summary of the responses provided.

### Factors influencing the representation of Māori with ASD

#### **1. There appear to be low numbers of Māori receiving ASD-related advice, information, and treatment. What factors contribute to this under-representation?**

The responses to this question can be grouped under seven main categories. These include the following:

- geographic isolation (access difficulties and isolation)
- insufficient knowledge and awareness of ASD
- lack of culturally appropriate professionals, services, and contexts
- funding and resource constraints
- lack of information available for whānau
- reluctance to seek treatment, or a delay in treatment seeking
- uniqueness of ASD.

Attendees to the hui identified geographic, economic, cultural, information and individual factors as to why it has been speculated that Māori children and young people appear to be under-represented with ASD.



## Assessment and diagnosis

### 2. What would be helpful and supportive during assessment and diagnosis?

Participants provided an extensive range of responses to this question. These are grouped under five main categories including:

- access to specialist services
- awareness and early intervention
- cultural education of professionals
- information
- whānau involvement and cultural processes.

Responses to this question were largely focused on cultural factors such as professionals being educated in a Māori world view, Māori frameworks of health such as Te Whare Tapa Whā, and the inclusion of Māori processes during assessment and diagnosis procedures. Whānau involvement and empowerment were also emphasised. Participants voiced the view that assessment should be undertaken in a friendly and appropriate environment and should proceed at a pace suitable to the whānau. It was suggested that the availability of a coordinator to support the whānau through the assessment process may improve current performance.

Reliable information being made available about expectations, treatment options, and availability of appropriate services was also mentioned. The need for explanations to be provided by professionals using plain language was noted, as was a need for the relationship between professionals and whānau to be based on trust and confidentiality.

Fewer responses were recorded regarding improved access to professional services. Of those that were noted, access to child and adolescent mental health services, Specialist Education Services (now Ministry of Education, Special Education (GSE)), and psychologists received mention.

### 3. What are some of the barriers for Māori accessing assessment and diagnosis services?

Responses to this question were very similar to those obtained for question 1. They are grouped under the following eight categories:

- differential diagnosis/misdiagnosis
- geographic isolation (access difficulties and isolation)
- funding and resource constraints
- lack of culturally appropriate professionals, services and contexts
- lack of information available for whānau
- lack of whānau support, the resource constraints of single parenting, or the needs of other children
- reluctance to seek treatment or a delay in treatment seeking
- time to access respite care from initial inquiry to first response.

The major focus of the participants was on cultural issues. Responses recorded included the need to recognise different cultural definitions of disability and spirituality, for professionals to be familiar with Māori world views, models of health and protocols, and the value of involving holistic treatments and tohunga in the provision of care. The concept of whakamā was also mentioned as a possible impediment that may influence delays in treatment seeking by parents or carers.

An observation was recorded involving the length of time it takes to receive accurate professional advice from first observation of a problem to the need to access respite care. Lack of whānau support, and single parenting, were noted as additional barriers. Problems with receiving accurate and timely information and referrals including professional advice on availability of services were also noted.

#### **4. Are these problems made harder because the person with ASD is Māori?**

There was a clear demarcation in responses to this question from hui participants. For those who agreed that assessment and diagnosis issues are more difficult because the person with ASD is Māori, responses fell into four categories. These were:

- geographic isolation (access difficulties and isolation)
- reluctance to seek treatment or a delay in treatment seeking
- lower socioeconomic status
- not trusting the system.

In contrast, those that disagreed with this statement believed that ethnicity was not a significant factor because services should be the same for Māori and non-Māori. It was also suggested that the main difficulty about assessment and diagnosis was when an individual received a diagnosis of ASD and the need for family members to come to terms with this.

#### **5. Identify any other Māori-specific issues or needs during assessment and diagnosis.**

Participants' responses to this question focused predominantly, yet broadly, on cultural factors. A further delineation of responses was therefore required to distinguish between the main issues raised. Responses were grouped under the following three categories:

- cultural protocol
- cultural frameworks
- organisational culture.

Participants of the hui almost unanimously responded to this question about Māori specific needs by identifying the implementation of Māori cultural protocols into the assessment and diagnosis process. Mirroring the process of pōwhiri, the responses included working in a kanohi ki te kanohi (face-to-face) format with whānau, and the provision of karanga, karakia and mihi to establish whanaungatanga, and waiata. The involvement of kaumātua and kuia was also noted, as was te reo Māori and tikanga Māori being made available to whānau during the assessment and diagnosis process.

Relative to cultural frameworks, emphasis was placed on professionals working with Māori with ASD and their whānau to do so within a holistic frame of reference. The main issue raised was for professionals to consider also the spiritual and emotional aspects of an individual being diagnosed with ASD along with the impact on their families.

The organisational cultural issues noted included providing support to kaupapa Māori organisations and other Māori agencies to undertake assessment with Māori. In addition, it was also suggested that the cultural competency of non-Māori clinicians to work effectively with Māori and their whānau ought to be examined.

Other responses to this question included the need for more funding to be directed to the field of ASD, a transparency of approach and the elimination of labelling relative to ASD.

**6. What would be the most important features of an effective assessment and diagnosis service for Māori children or adults with ASD?**

The direct responses to this question are as follows:

- whakawhanaungatanga, aroha, tika, pono, manaaki
- empowering and supporting the whānau
- when a parent receives a diagnosis of ASD, the funding should be there through a Māori parent network so that another Māori parent can offer support, information and advice.

The major theme reiterated by participants was the need for assessment and diagnosis services to be provided in a supportive environment where individuals and whānau could access cultural protocols and practices. Allowing whānau to take ownership of the process was noted as a potential feature of empowerment.

**Post-diagnosis support**

**7. For parents and whānau, coming to terms with the implications of a diagnosis of ASD can be a very difficult process. What kind of post-diagnosis support would be most helpful?**

The responses to this question were structured into four main categories. These include:

- cultural factors
- organisational factors
- information
- emotional support.

Relative to cultural factors, attendees considered that post-diagnosis support would be best achieved by including a holistic approach involving kaumātua and kuia and supporting a by-Māori-for-Māori service. Having total whānau involvement along with a coordinator, preferably well versed in Māori protocol, to support whānau in the post-diagnosis process was also considered helpful.

Organisational factors suggested included there being a need for good intersectoral relationships across the services to assist Māori. Interagency sharing of information from which Māori could benefit by having improvements to their care across a number of sectors was mentioned. Regarding emotional factors, explicit references were made to affective responses experienced by whānau at post-diagnosis including: relief, anxiety, guilt, inferior feelings, whakamā, stress, stigmatising attitudes, frustration, embarrassment and self-blame. Counselling and education services were noted as being two areas where more attention could be directed towards improving emotional support for Māori with ASD and their whānau. In addition, the issue of raising awareness about nutrition and general healthy lifestyles for Māori was also recorded.

**8. What are some of the barriers or difficulties at this time?**

The main response noted relative to this question was that currently there is a lack of trained Māori in specialist areas such as health, education and iwi organisations who could provide culturally appropriate support at post-diagnosis. It was suggested that the provision of scholarships could enhance Māori representation in these areas. Other responses reiterated the call for improvements in the wider dissemination of clear information. Suggestions for improving information included:

- the use of relevant and appropriate language to describe ASD and its likely lifespan developmental course
- availability of services across sectors and in specific regions
- funding and resources
- how whānau can best provide for the needs of an individual with ASD.

**9. Identify any Māori-specific issues or needs during post-diagnosis support.**

The responses to this question included there being a lack of continuity in service provision from a diagnosis of ASD and therapy, and a need to consider a grieving period for Māori on receipt of their child or whānau member receiving a diagnosis of ASD. Providing to the cultural needs of whānau post-diagnosis was also emphasised, along with the need for professionals to have dual clinical and cultural competence when attending to the needs of Māori with ASD and their whānau.

**Kaiarahi**

**10. The need for a kaiarahi (guide) was identified in the development of the background information for the ASD hui. The role of the kaiarahi is to guide whānau through their encounters with the system. What are your views on the role of a kaiarahi and do you support the need for this role in ASD-related services?**

Responses to these questions are grouped in to four distinct categories. These are:

- cultural factors
- policy factors
- Strengthening Families model
- whānau model.

Many participants responded yes – that the appointment of a kaiarahi would be of

value. The ability to work confidently and competently with whānau so that they could be empowered was seen as paramount. This involved being able to develop a working protocol in conjunction with the whānau and also being able to provide quality information, advocacy and whānau support. Having an understanding of cultural factors was seen as important. Many cited partnership, protection and participation as guiding principles that could be used to develop a bicultural service. Other attendees cited a preference for the Strengthening Families model to be implemented rather than appointing a kaiarahi. The reasons given for the favouring of this model over the appointment of a kaiarahi included there being too many people involved already from early ASD diagnosis and that the Strengthening Families approach allowed for an inclusive approach where whānau remained at the centre of the process.

**Education**

**11. How can parents and whānau be assisted to participate fully in educational decision-making for their son or daughter with ASD?**

Participants' responses to this question fell into four different, but related, categories. These are:

- availability of professional support and services
- communication and information factors
- early identification and involvement
- time and transition.

Attendees at the hui clearly favoured the opportunity to more fully participate in educational decision-making. Involvement of the whānau was emphasised as was being given a range of options about educational services available to their child. It was noted that this information

should be provided to the parent, carer and whānau as soon as possible from the point of first diagnosis. A more streamlined approach was called for across the various educational programmes and services to facilitate continuity and consistency of education for children with ASD. This was deemed particularly important, as transitions across different educational environments and their success (or otherwise) can lead to stressful times for the child involved, their families, and professionals. It was suggested that an education package could be developed for whānau describing the various educational services available to them along with explicit information about programme requirements including funding. Providing parents and carers with the choice of where they would prefer the Individual Education Programme (IEP) to be undertaken was also noted, as was the requirement that the cultural choices of whānau for their members with ASD be respected.

## **12. What are some of the barriers or difficulties associated with participating in education decision-making?**

Responses to this question fell into five categories. These are:

- assessment issues
- environmental factors
- information factors
- resource constraints
- negative emotion and experience.

In terms of assessment issues, some participants felt that application forms needing to be completed to receive education services were barriers for Māori. Others thought that the high number of assessments needing to be undertaken would prevent fuller participation by Māori. It was noted that there seems to be additional support

provided to more severe cases of ASD and not the same level of support given to less severe cases such as Asperger syndrome. Regarding environmental factors, it was suggested that some schools are special-education-needs phobic, they continue to be monocultural in both tone and practice and that there is a lack of integration between the school and home environments. The use of jargon by professionals and the number of personnel involved in assessment were also presented as barriers. The need to clarify professionals' respective roles in the educational assessment process was suggested. A lack of resources, such as not having suitable transport available, was also cited as a barrier. Negative emotions, including grief and anger about the diagnosis, were noted as influencing participation; as was the parents' own prior negative experience in the educational system. With regard to the latter, it was suggested that the negative educational experience of parents could directly influence whether they wanted to be involved in their child's education.

## **13. Identify any Māori-specific issues or needs during the process.**

Responses to this question closely resemble those received for question 2. Two categories were used to organise the responses. These are:

- communication and information factors
- cultural factors.

Specific issues or needs of Māori included information being delivered in a clear, precise and meaningful way. Particular attention to communication and information factors should be paid by multidisciplinary teams when working with whānau. It was suggested that handouts might be useful in this regard, especially if they included illustrations and were written in language that was

relevant, appropriate and accessible to the public. Moreover, it was also pointed out that provision of information to Māori should not be rushed, and when imparting information it should not be assumed that silence indicates agreement. Encouraging whānau to take support persons with them when they attend meetings was also noted.

The use of cultural protocols such as karakia was cited as being relevant to the process as were an understanding of whakawhanaungatanga and the upholding of the mana of the whānau during the process. Consultation with elders or the inclusion of a kaiarahi to guide and assist professionals working with whānau may improve the process.

**14. Parents and whānau may need training and support to work on educational interventions with their son or daughter with ASD, for example, learning new skills to support generalising communication goals to the home or marae setting. Describe culturally appropriate ways of providing support and involving parents and whānau in educational interventions.**

The responses to this question were organised into three categories, namely:

- home-based support
- information support
- marae-based support.

Some participants thought that the best way to involve parents and whānau in educational interventions was to improve home-support initiatives. These included a kaiarahi making home visits to whānau, identifying the current skill-base of whānau in collaboration with service providers, and providing the opportunity for parents to access education and resources to become skilled in intervention. With respect to the latter point, a process was suggested whereby

the kaiarahi, service provider, whānau and individual with ASD could together engage in cultural activities such as raranga, taiaha, haka, waiata, waka-ama and poi. This would potentially engender and facilitate a more collaborative approach.

It was also mentioned that the provision of childcare for other siblings when the parent is upskilling would be helpful, as would be making transport available along with kai. It was noted that providing educational resources that parents could use or make themselves would be useful.

In addition, participants suggested that information support for parents and whānau could be improved. It was suggested that the setting up of an ASD 0800 support or text line where information from a Māori perspective was provided, including information about treatments such as natural remedies, might improve participation. To facilitate a more collaborative approach it was also proposed that a marae-based environment might encourage greater family/whānau participation. Kōhanga were also suggested as another culturally appropriate setting. Within these settings, whānau may feel more comfortable and material could also be provided in te reo Māori.

**15. Lack of eye gaze from a young Māori child could be an example of where someone's cultural background could be misinterpreted as a communication problem. Are you aware of any other examples of possible cultural or communication understandings?**

The responses received to this question were grouped into three main categories. These are:

- communication factors
- contextual factors
- cultural factors.

Hui participants mentioned that it was important that professionals listen to families, and limit their use of technical language and terminology when working with whānau. While not culturally specific, participants offered the view that the Māori child with ASD may lack a range of communication skills including the ability to effectively comprehend verbal and non-verbal behaviours. They may also have hearing loss and not be able to communicate using sign language. Some individuals are tactile defensive. Also noted was that there are both positive and negative impacts from stigma surrounding the thoughts and myths attached to ASD.

A range of contextual factors was also cited as being worthy of note. Included among these was the need for professionals to examine the background of the child presenting. It was suggested that the reason for the child's social withdrawal might be because they were raised in a dysfunctional environment. Reiterating this opinion was the call for experts to pay careful attention to how the child presents to professional services.

Regarding cultural factors, participants offered the view that there might be a mismatch of models between whānau and professionals relative to child development. There may also be a mismatch between services and expectations of outputs. This was described as a differential in 'cultural pace' between the expectations of professionals and those of the whānau. How whānau view the spirituality of the child with ASD in relation to their world view was also posited as a cultural consideration.

## Services and ongoing support

### **16. People with ASD use a wide range of services within the disability sector. What are some of the barriers for Māori accessing disability support services?**

Attendees to the hui gave similar responses to this question as those obtained for question 1. These included the following categories:

- geographic isolation (access difficulties and isolation)
- funding and resource constraints
- lack of culturally appropriate professionals, services, and contexts
- lack of information available for whānau
- lack of whānau support, the resource constraints of single parenting, or the needs of other children
- reluctance to seek treatment, or a delay in treatment seeking.

Isolation from appropriate services was cited as a possible barrier, as was not having access to much-needed resources such as a telephone and transport. Relative to culturally appropriate services, the provision of 'Māori services for Māori people' was discussed along with making available kaupapa Māori services for children and young people up to the age of 15 years. Culturally appropriate day services and respite and residential placements were also called for. A request to extend the choices and improve the provision of community-based professional support was noted.



Once again it was also suggested that there might be a discrepancy in funding between children with severe ASD and those who are 'higher functioning' individuals. A lack of clear information about available services, how they can be accessed and the rights of parents were cited as possible barriers, as were difficulties in identifying where the responsibilities and boundaries existed across government agencies providing ASD services. It was also noted that late diagnosis of ASD might prove to be a barrier for Māori accessing disability support services. About this, it was suggested that there might be reluctance on the part of whānau to accept the initial diagnosis especially if they lack trust in the health system and of health professionals. If they do not accept the diagnosis it is unlikely that they will access the appropriate services.

**17. What are some of the most significant service gaps for Māori and how could these gaps be addressed?**

This two-part question received a range of responses that were similar to those obtained for question 1. Answers to the first part of the question regarding current gaps in disability support services were grouped into the following three categories:

- emotional response
- lack of culturally appropriate professionals, services, and contexts
- lack of information and support available for whānau.

It was suggested that whānau need the time to grieve after their child has received a diagnosis of ASD. This emotional response represents an important transitional event for whānau and should be respected. Consistent with the responses from the other key areas, it was also noted that there should be more choices made readily available to Māori

such as kaupapa Māori services. It was also suggested that Māori continue to fall through the gaps because regular services are inaccessible to Māori. Limited information being made available to Māori about ASD was also mentioned. Two examples that illustrate this gap in services are adults leaving home before receiving a diagnosis and children not receiving teacher aide support in regular schools. More information about support was required that described who whānau could contact, where to contact them and what kind of support and programmes were available.

The second part of this question involved identifying how some of the gaps could be addressed. Suggestions made by participants were grouped into two broad categories. These included:

- cultural factors
- national initiatives.

It was suggested that gaps in current Māori disability services could be improved by providing cultural training to all clinicians, paediatricians and nurses. Participants also felt that there was a need to train more Māori to become paediatricians and nurses so that they could become specialists in the ASD field. In addition it was also mentioned that whānau partnerships could be developed that encouraged community collaboration and service integration.

The provision of disability support to Māori could also be undertaken under the umbrella of the marae. By providing services on the marae, whānau might be encouraged to more effectively participate, especially if pōwhiri and other cultural protocols were employed to make them feel more comfortable. Another focus from the hui was on improving Māori provider and workforce development including encouraging more Māori to enter training programmes in specialist ASD services as



noted above. The need to identify community support mechanisms already available through existing Māori health providers was also suggested. The relevance of working with Māori in a consultative and collaborative way including sharing information and networking was also posited as a possible avenue to improve current gaps.

There were also a variety of national-level initiatives suggested by participants. This included an intersectoral review to research government systemic processes that might either enable or encourage health sector fragmentation. It was also suggested that a national register of professionals with expertise in ASD could be developed, which might strengthen awareness and understanding of ASD across government agencies. Moreover, this might lead to government funding being extended from diagnosis to the provision of ongoing funding and support. Participants also advocated the need for a public-awareness campaign about ASD. It was proposed that such a campaign could draw usefully from the 'Like minds, like mine' destigmatisation of mental health programme. Positive messages about ASD could be specifically directed towards raising awareness of ASD in a public forum and reach a wider national audience including parents and representatives of government agencies.

#### **18. What kind of ongoing support would be most helpful during the transitions and changes facing Māori children, young people and adults with ASD?**

Attendees at the hui provided an extensive range of suggestions to this question. These were arranged into the following four categories:

- contextual or environmental factors
- cultural factors
- funding and resource constraints
- support factors.

In terms of contextual and environmental factors, participants identified important transitions for Māori children with ASD as occurring with changes from early childhood education services to school, from school to work and from home to independent living. Issues for the transition from early childhood education services to school involved a lack of environmental skills being provided to children with ASD to cope successfully with the transition, a lack of staff awareness of the necessity for these skills to be developed and the problem of schools not being able to effectively manage the transition. Acknowledgement was also made that individuals with ASD in the school environment may be considered a burden by teachers who may not be sufficiently skilled to manage these children in the educational environment.

Regarding the transition from school to work, participants suggested that there is a gap in teaching appropriate life skills to adolescents with ASD in the 17 to 20 years age bracket. For the transition from home to independent living, responses focused on the need for services to be available to provide ongoing support for independent living as well as support to find the right job for the individual.

Cultural factors raised during the hui involved empowering the whānau through acknowledging and respecting cultural protocols and the need for services that involved alternative treatments. Advocacy services provided by iwi organisations and Māori providers also needed more attention such as developing services appropriate for individuals with ASD and their whānau. Relative to funding, participants suggested that regular reviews of resource allocation for ASD should be undertaken. Such reviews would involve identifying whether adequate resources were being provided to the ASD field and whether there was sufficient funding being made available to parents to attend courses.

Regarding support factors, attendees proposed that there is a need for intensive support to be made available to whānau during the change and transition phases. It was suggested that a nominated support person could be made available, or alternatively, whānau members who had been through the respective transitions themselves could provide support. Another important factor noted was that during these stages, whānau could be supported through the setting-up of workshops to provide education about ASD, cultural training and funding information. Other workshops might involve education for professionals and employers who work with individuals with ASD and their whānau. A feature of such workshops would be to destigmatise ASD and challenge negative stereotypes about the condition.

**19. Respite is a theme in the background information for the ASD hui. What are some of the most important features of an effective respite service for Māori children or adults with ASD?**

Responses to this question were grouped into three main categories. These included:

- availability issues
- cultural factors
- funding and resource constraints.

Hui participants considered that there were issues involving the availability of respite care for Māori. These involved difficulties in finding Māori carers and people who have an understanding of ASD. It was suggested that there needs to be a network of people to provide respite care, that there should be professional respite care areas made available, along with suitable allocation of time to undertake professional respite care. It was also noted that these issues were further compounded by the need to pay whānau

to provide respite care, even though accepting payment was not generally seen as the correct way of doing things. Moreover, whānau may be reluctant to access respite care services through feelings of whakamā.

Other attendees at the hui thought that respite care services could be strengthened by providing broader options such as a kaupapa Māori respite service and a whānau-centred respite service. This undertaking would involve all the needs of whānau being taken into account and ensure that the services were both person and whānau centred. In relation to this suggestion, it was suggested that regional service providers and Māori providers could be used as valuable models by which Māori respite services could be developed. In addition, it was also suggested that respite care could be offered in family/whānau settings and that marae-based training could be provided for family carers. A call was also made for there being made available crisis respite care for Māori.

Relative to funding and resource constraints, attendees at the hui mentioned that if government funding was specifically targeted towards ASD, then this could potentially lead to the strengthening of a community's capacity to provide support and respite care to whānau. It was also noted that there may be constraints in accessing appropriate respite care services if an individual had a dual diagnosis.

## Information

### **20. People often stress the importance of timely, accurate and sensitive information. Are there any cultural considerations about the way ASD information is provided?**

The following suggestions were made relative to this question:

- make available wānanga in the respective regions and communities
- invite community based ownership of sourcing and distributing information
- provide ASD information in te reo Māori
- develop a mainstream information package. This would contain different strategies for managing ASD behaviour so that services could provide adequate support to people with ASD
- develop a Māori information package. This would describe what ASD is and what it means
- deliver information kanohi ki te kanohi (face-to-face).

It was also suggested that caution should be exhibited about when the appropriate time was to provide information to Māori about ASD. It was noted that for some Māori, a pause is needed after a diagnosis of ASD has been received, so that they have sufficient time to grieve. Providing a lot of information immediately after a diagnosis of ASD has been given may simply overwhelm them. The need to provide accurate information about what parents and carers could expect during the course of development over the lifespan for their family member with ASD was also mentioned.

### **21. How could ASD-related information be made more accessible and more useful to Māori?**

A number of different responses were provided to this question. These included:

- development of a video featuring kaumātua who could describe the issues involving ASD. The video should be made available in English and te reo Māori and show different contexts to deliver the messages, including marae
- access to Plunket and similar services to identify early indicators
- preparation of an information pack that may include a range of written and visual resources and dissemination of this material through organisations and communities
- presentation of ASD information through the media (eg, television, radio) with well-known personalities and presenters delivering the information
- provision of workshops presenting a range of information about ASD assessment and diagnosis, post-diagnosis support, education and disabilities support.

## ASD Guideline development

**22. The key themes from all five hui will be analysed and incorporated with other Māori research and information into a Māori section in the draft ASD Guideline. A Māori writer/researcher will be funded to undertake this work following the completion of the hui. Do you support the development of a Māori section in the ASD Guideline?**

All responses to this question positively endorsed the inclusion of a chapter on Māori for this guideline. Various reasons were given for this view, including: raising awareness of cultural differences and needs, a lack of access to information for Māori in the past, the need to understand Māori to provide good support to Māori with ASD, and that the Ministries involved in this project had an obligation under the Treaty of Waitangi to include such information.

## Open-ended discussion

**23. Are there any other ASD-related issues that are important to you that we have not already discussed?**

The primary set of issues raised by the participants is as follows:

- questions and research should focus on the systemic and structural issues pertaining to the health system's inability to understand Māori needs, rather than using a blaming Māori approach
- the need for ASD hui that are more inclusive of parents and whānau
- Māori communities need to ask themselves what support they offer to Māori with ASD. How do rūnanga, for example, provide support to Māori with disabilities?
- a concern that the Ministry took a top-down approach rather than a bottom-up approach, which would involve including perspectives of parents and Māori service providers
- monocultural service frameworks are not sufficient for the development of a Māori service. It needs to come from Māori for Māori
- that autism or similar types of conditions are often seen as normal and life reflects that. Kawa and tikanga can accommodate whānau with ASD
- questions about the funding for the ASD Guideline and what is going to happen once the guideline is completed. Will there be extra resources made available?
- current funding is both a barrier and a gap – the flat level of non-negotiable funding does not take into account the individual needs and the four dimensions of a person with ASD including:
  - their age
  - whether they are Māori or non-Māori
  - their ASD
  - them as an individual
- Māori children with ASD are seen as a gift and embraced in whānau
- information from the hui should go to the policy makers.

## Part 8

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### Pacific peoples' perspective

“Being a parent to a son with autism, is about the importance of having our son being part of and being accepted for who he is in a number of communities, not just our own nuclear family, school, church communities and wider community in general. It really does take a village to raise a child.”

## Part 8 Pacific peoples' perspectives

### Summary of recommendations

Good Practice Points:		
8.1	The role of the family, extended family and community should be acknowledged and empowered by identifying attitudes and beliefs that the individual and family have surrounding ASD.	✓
8.2	Appropriate educational material in language appropriate to each specific Pacific Island group should be provided to enhance understanding of ASD and support services they may be eligible for.	✓
8.3	Pacific support workers, carers, teacher aides, cultural workers and/or clinicians should be involved from the point of assessment and diagnosis through to coordination and treatment.	✓
8.4	The establishment of Pacific community support networks specific to ASD in appropriate geographical locations should be facilitated.	✓
8.5	Services must be proactive in offering treatment.	✓
8.6	Decision-making regarding assessment, treatment and coordination should be based on contextual information from a variety of sources and include specific Pacific input.	✓
8.7	A programme of research that would provide baseline information regarding ASD and Pacific people should be developed.	✓
8.8	A targeted recruitment and development strategy to support increasing the capacity and capability of the Pacific ASD-related workforce should be developed.	✓
8.9	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.	✓

There is no robust formal research to date that addresses issues of ASD in a Pacific population yet anecdotal evidence, expert opinion and qualitative reports identify that ASD also affects Pacific people. However, there is clear empirical evidence that Pacific people have poorer health status, are exposed to more risk factors for poor health and experience barriers to accessing services.<sup>424</sup>

The Pacific Health and Disability Action Plan<sup>425</sup> sets out the strategic direction and actions for improving health outcomes for Pacific peoples and reducing inequalities between Pacific and non-Pacific peoples. Promoting participation of Pacific peoples is a key priority, with a focus on increasing access and quality of support services for Pacific people as well as encouraging community-based plans for disability issues. The inclusion of the Pacific section in this guideline is aligned with this priority.

Due to migration, 6.9% of New Zealand's total population is of Pacific ethnicity (or 265,974 people).<sup>426</sup> The 2006 New Zealand Census reports that 131,103 of the Pacific population (almost half) are Samoan, followed by Cook Island Māori (58,008), Tongan (50,481), Niuean (22,476), Fijian (9864), Tokelauan (6819) and Tuvaluan (2628). The majority of this population was born in New Zealand with about two-thirds of the population located in the Auckland region.<sup>426</sup> The Pacific population is a very youthful population with the 0 to 14 year old age group accounting for 37.7% of the entire Pacific population. Young Pacific people are also more likely to belong to more than one ethnic group.

This part of the New Zealand ASD Guideline provides a broad overview of issues, using a pan-Pacific approach. It is important, however, to recognise and acknowledge the cultural diversity between and within Pacific cultures – each nation has its own specific set of cultural beliefs,

customs, values and traditions. The status, authority, tradition, obligations and power structures are different for each group.<sup>427</sup> Moreover, the level of acculturation of a Pacific person will determine the extent to which this chapter applies. World views of New Zealand-born Pacific youth may be intrinsically different as identity may include affiliation to both western and traditional Pacific practices and values. There also may be intergenerational tensions that exist between traditional and youth cultures.

There is no formal research to date that addresses issues of ASD in a Pacific population and, in line with mainstream epidemiological research, the incidence and prevalence of ASD in the Pacific population within New Zealand is unknown. Research on general disability and Pacific people living in New Zealand estimates that one in seven (or 28,100) Pacific people has a disability, of which 21% are children. The research report also estimates that 72% of Pacific people with disability live in the most socioeconomically deprived areas of New Zealand.<sup>428</sup>

The recommendations contained in this section are derived from public reports, guidelines and published statistics and consultation through a *fono*.

## 8.1 Pacific concepts of health

Common values across Pacific nations are ideals such as respect, reciprocity, communalism, collective responsibility, humility, love, service and spirituality.<sup>429</sup> Pan-Pacific concepts of family emphasise collectivity and encompass the immediate and extended family as well as the wider community – it is not uncommon for children to be raised or parented by aunts, uncles or grandparents.

Traditional Pacific concepts of health are holistic, where wellbeing is defined by the equilibrium of mind, body, spirituality, family and environment. Traditionally, Pacific people view disturbed behaviour or mental illness as a manifestation of an external spiritual force that is usually caused by a breach of a sacred covenant between people or between people and the gods – hence treatment was sought from a traditional healer.<sup>430</sup> Accordingly, traditional explanations of disability have been based on cosmological and spiritual connections such as punishment from God or a curse due to a family wrong.

Pacific people have historically had low access and utilisation rates of disability support services in general.<sup>431</sup> One contributing factor is thought to be the high degree of stigma attached to disability in Pacific cultures, so that the presence of disability is seen as shaming for the family.<sup>139</sup> The shame is often associated with beliefs around breach of tapu and punishment for wrongs. Entrenched traditional beliefs and stigma issues inherent in most Pacific cultures, with regards to relating to people with disabilities, act as a major barrier to full acceptance and participation in society and to accessing disability services in particular.

Duty of care for loved ones is sacrosanct in most Pacific cultures where ultimate responsibility for the sick or disabled traditionally falls on the immediate and extended family. This may be a tremendous support and strength of Pacific families; however, it could act as a barrier to accessing services<sup>139</sup> and, as regards ASD, may prevent severe difficulties from being identified early.<sup>138</sup> Furthermore, the guilt and shame associated with an inability (or perceived unwillingness) to bear the full burden of care increases the chances that services may not be accessed.

Qualitative information suggests that ASD may not be acknowledged as 'ASD' in Pacific communities where a child that is 'different' may just be accepted as 'an odd one' and medical help and other supports may not be seen as needed or a priority. Moreover, there may be perceptions that a Pacific child with ASD may 'grow out of it', or may be seen as just 'a naughty child'.<sup>138</sup> Compounding the situation further is the fact that Pacific people are disproportionately over-represented in most negative socioeconomic indicators when compared to the general population. Poverty itself is a barrier to accessing services and there may simply be 'more pressing needs' related to surviving, rather than dealing with a 'problem child'.<sup>138</sup>



## 8.2 Considerations when dealing with Pacific people with ASD

- Acknowledge and empower the role of the family, extended family and community. Clinicians and other workers may need to identify attitudes and beliefs that the individual and family have with regards to ASD before carrying out assessment and incorporate this into the treatment plan.
- Provide appropriate education for Pacific families who may be vulnerable to misunderstanding ASD and ASD services. Material written in English is not culturally appropriate for Pacific people with their oral tradition and understanding the messages requires too high a proficiency in written English.<sup>139</sup> All written material should be produced in Pacific languages as well as in oral form (eg, videos), where possible. Language interpreters should be offered, regardless of perceived proficiency in English.
- Involve Pacific support workers, carers, teacher aides, cultural workers and/or clinicians from the point of assessment and diagnosis through to coordination and treatment. While a 'Pacific for Pacific' approach is ideal, this may not be realistic (given the under-representation of Pacific workers in the field), and mainstream services should coordinate and establish partnerships with Pacific providers. Both mainstream and Pacific workers may require cultural competency training as well as training in ASD-specific knowledge.
- Facilitate the establishment of Pacific community support networks specific to ASD in appropriate geographical locations.
- Provide proactive treatment planning where services are offered to families, rather than expecting them to initiate contact and ask for it. Socioeconomic circumstances should be considered.
- Use standardised tests with Pacific people with caution – particularly tools used for the assessment of ASD. Pacific people have not been included in the populations that the instruments are normed on, giving rise to inaccurate and invalid conclusions. Cultural protocol and behavioural norms also need to be acknowledged and not misunderstood in relation to ASD symptomatology. Any decision-making regarding assessment, treatment and coordination should be based on contextual information from a variety of sources, should consider natural settings and environment and should include Pacific input.

### 8.3 Research and workforce development

Given the paucity of research in the area of ASD and Pacific people, the contents of this chapter merely symbolise a starting point for the Pacific ASD community and sector.

Robust research investigating ASD in the Pacific population is urgently needed, particularly epidemiological information identifying the prevalence and extent of ASD occurring in the Pacific population. Qualitative information is also required to gain a deeper understanding and knowledge of the presentation and nature of ASD among Pacific people, including intra-ethnic differences and similarities between Pacific Islands nations, and also between younger and older, more traditional Pacific people.

From the start, this research should be framed to translate into policy, inform best-practice guidelines and provide information to funders for resource allocation.

Although this section of the New Zealand ASD Guideline recommends involving Pacific people in the assessment and treatment process, it acknowledges that there is a paucity of Pacific people working in the health and disability workforce. There is an urgent need to increase the capacity and capability of the Pacific ASD-related workforce, in particular the professional workforce (rather than the non-regulated workforce in which Pacific people feature more frequently). This would require a recruitment and development strategy specifically targeted at Pacific people. In parallel with this, there is a need to improve the cultural competency of the mainstream workforce so that clinicians, teachers, support workers and carers are working in a more appropriate and effective way.

Increasing Pacific workforce numbers and enhancing cultural competency is likely to increase access rates for Pacific families and will contribute to providing culturally appropriate services, more effective treatment and ultimately better outcomes for Pacific people with ASD and their families.

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

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## Glossary

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

## Glossary

### Glossary of terms and abbreviations

<b>Accident Compensation Corporation (ACC)</b>	Accident Compensation Corporation
<b>Accommodations</b>	making exceptions, adaptations or accommodations to the curriculum or environment
<b>Adaptations</b>	changes to accommodate the student's needs or preferences
<b>Adaptive behaviour/skills</b>	an individual's ability to act appropriately in social situations and to take care of their personal needs
<b>Adult-directed</b>	the adult decides on the goals, materials and teaching strategies and gives instructions (usually without consideration of child preference)
<b>Advocacy</b>	speaking, acting and writing with minimal conflict of interest on behalf of the sincerely perceived interests of a disadvantaged person to promote, protect and defend their welfare and justice. There are different types of advocacy: independent, individual, informal, self and systemic advocacy.
<b>Aetiology</b>	study of the causes of diseases or disorders
<b>Age-appropriate</b>	activities, materials, curriculum and environment consistent with the chronological age of the child
<b>Agranulocytosis</b>	a decrease in the number of or absence of granulocytes in the peripheral blood. Granulocytes are also known as polymorphonuclear cells and neutrophils. Granulocytes are a type of white blood cell and are very important in the body's defence against bacterial infections
<b>Aided symbol use</b>	see augmentative communication
<b>Akathisia</b>	a movement disorder characterised by restlessness and an inability to sit or stand still
<b>Animal therapy</b>	contact with animals (eg, riding horses, swimming with dolphins) as therapy
<b>Anorectic</b>	lacking in appetite
<b>Anorexia</b>	lacking in appetite. The term is most commonly used with respect to eating and the disorder, anorexia nervosa.
<b>Anorexia nervosa</b>	an eating disorder characterised by intense fear of becoming obese, dramatic weight loss, obsessive concern with one's weight, disturbances of body image such that the patient 'feels fat' when of normal weight or even emaciated, and, in females, amenorrhea

<b>Applied behaviour analysis (ABA)</b>	<p>the Living Guideline Group provided this definition following their update on applied behaviour analysis.<sup>12</sup></p> <p>The experimental analysis of behaviour is a scientific approach to the discovery of environmental variables that reliably influence behaviour; applied behaviour analysis is the systematic application of these principles in socially significant contexts. In practice, applied behaviour analysis is not a single method or type of therapy; it refers to a collection of methods and techniques designed to increase positive behaviours and decrease negative ones. Common techniques include (a) reinforcement (contingency management, including extinction); (b) shaping and chaining (teaching components of more complex skills); (c) establishing stimulus control (discrimination training); (d) fading of prompts, cues, and physical assistance. Behavioural interventions designed to decrease negative (excess) behaviours require careful assessment of the function of the behaviour of interest (how it is being controlled by antecedents and consequences, or in other words, what function is it serving for the individual). Interventions designed to increase positive behaviours (eg, teaching new skills) require assessment of the components of the skill (task analysis), the social validity or importance for the individual's development, its acceptability to the individual and his or her social network (eg, family, culture), and the likelihood that the new behaviour will result in positive natural consequences.</p> <p>Good assessment ensures that the behaviour change resulting from the intervention programme will ideally be maintained once the programme is no longer in effect, and that the behaviour will generalise to new settings other than the training context. For interventions to meet the definition of ABA, the behaviour change (outcomes for the individual) should be systematically monitored. Professionals trained in delivering ABA do not follow a rigid formula or protocol, but will individually design and modify procedures according to well-established behavioural principles. Further discussion of how interventions are judged to meet these characteristics were provided in the two literature reviews, which also cited additional references that help to define these terms.</p> <p>It has become quite common for highly structured, intensive early intervention programmes to be called 'ABA' however this is not correct, since ABA refers to a wide variety of techniques and principles.</p>
<b>Arrhythmia</b>	an abnormality of the normal heart rhythm
<b>Art therapy</b>	art as nonverbal, symbolic means for a person with ASD to express him/herself

<b>Asperger syndrome (AS)</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>Assistive technology (AT)</b>	defined as any device used to support the functional capabilities of individuals with disabilities. AT includes computer-assisted instruction, mobility devices, high and low technology adaptations and augmentative communication.
<b>Attention deficit hyperactivity disorder (ADHD)</b>	a disorder of attention to task, characterised by difficulty completing tasks in all settings, and often associated with hyperactive behaviour
<b>Audiologist</b>	a health care professional who is trained to evaluate hearing loss and related disorders, and to rehabilitate individuals with hearing loss and related disorders. An audiologist uses a variety of tests and procedures to assess hearing and balance function and to fit and dispense hearing aids and other assistive devices for hearing.
<b>Audiology</b>	the assessment of hearing loss and disorders. Also the study of hearing disorders.
<b>Auditory integration training (AIT)</b>	an auditory technique which works on the concept that hypersensitivities and processing abilities can be remediated by modulated/filtered music provided through earphones
<b>Auditory processing</b>	processing information which is received aurally
<b>Augmentative and alternative communication (AAC)</b>	frequently simply referred to as augmentative communication (AC). Compensating for impairments in individuals with expressive communication disorders. It might include supporting or developing communication with sign language, visual symbols, or voice output devices.
<b>Autism spectrum disorder (ASD)</b>	<p>Autism Spectrum Disorder (ASD) is a condition that affects communication, social interaction and adaptive behaviour functioning. As specified in the current version of the Diagnostic and Statistical Manual for Mental Disorders, the DSM-5,<sup>18</sup> all people who are diagnosed with ASD share characteristics in two domains: impairment in social communication or social reciprocity, and impairment in restricted, repetitive patterns of behaviour.</p> <p>Although these features are characteristic of all people with ASD, it is a very heterogeneous condition affecting a very diverse group of individuals with a wide range of severity, disability and intellectual function, from the severely impaired person to a 'high functioning' individual.</p>

<b>Autism</b>	characterised by more profound impairments in communication, social and restricted interests, activities and behaviours. May include intellectual impairment.
<b>Aversive measures/procedures</b>	behavioural methods employing punishment or the withdrawal of privileges, rather than positive reinforcement
<b>Backward chaining</b>	steps to performing a task are identified – the last step is taught first and this process is continued until all the steps are learned
<b>Behaviour</b>	<p>an individual's reaction in any given situation, or to any given response, or, a generic term covering acts, activities, responses, reactions, movements, processes and any other measurable response.</p> <p>The behaviour of people is studied by a number of disciplines including the academic disciplines of psychology (including applied behaviour analysis), sociology, economics, and anthropology.</p>
<b>Behaviour analysis</b>	the scientific study of behaviour. BF Skinner, generally considered the founder of behaviour analysis, coined the term 'behaviour analysis'. The term was meant to distinguish the field as one that focuses on behaviour as a subject in its own right, rather than as an index or manifestation of something happening at some other level (in the mind, brain, psyche, etc).
<b>Behaviour management</b>	the systematic manipulation of environmental stimuli or events to increase the likelihood that an individual, or group of individuals, will exhibit appropriate behaviours and to reduce the likelihood that an individual, or group of individuals, will exhibit inappropriate behaviours
<b>Biomedical</b>	an umbrella term for those interventions which have a medical, biochemical or dietary basis, but are not pharmacological
<b>Bipolar disorder</b>	a major affective disorder in which both manic and depressive episodes occur
<b>Body language</b>	communication that occurs as a result of using gestures, posture etc
<b>Capacity building</b>	to improve organisational ability/capacity to respond to a particular need, or meet a demand
<b>Cardiotoxicity</b>	having a direct toxic or adverse effect on the heart
<b>Caries</b>	tooth decay, cavities
<b>Cartooning</b>	use of cartoons to enhance social understanding, for example, by drawing thought bubbles to show what someone is thinking

<b>Challenging behaviour</b>	behaviour of such frequency, intensity or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities
<b>Chelation</b>	administration of a chemical compound to bind a metal so that the metal can be eliminated from the body
<b>Child, Adolescent and Family Services (CAFS)</b>	mental health services for children and adolescents. Also referred to as Child and Adolescent Mental Health Services.
<b>Child, Youth and Family (CYF)</b>	Child, Youth and Family, a service of the Ministry of Social Development
<b>Children and Adolescents Mental Health Statewide Network (CAMHSNET)</b>	Children and Adolescents Mental Health Statewide Network
<b>Child-centred</b>	the goals, materials and teaching strategies are determined with consideration of the child's interests and preferences
<b>Child-led</b>	the activities follow the child's lead or interest
<b>Circle of Friends</b>	a programme for developing a support group of peers around the child
<b>Cognition</b>	general term for the processes involved in thinking
<b>Cognitive assessment</b>	assessment of the processes of cognitive or intellectual functioning, including verbal comprehension, perceptual organisation, working memory and processing speed. Can include specific tests of perception, reasoning, problem solving and memory.
<b>Cognitive behaviour therapy (CBT)</b>	psychotherapy based on modifying everyday thoughts and behaviours, with the aim of positively influencing emotions. CBT developed out of behaviour modification and Cognitive Therapy, and is widely used to treat mental disorders. Therapeutic techniques vary according to the particular kind of client or issue, but commonly include keeping a diary of significant events and associated feelings, thoughts and behaviours; questioning and testing assumptions or habits of thought that might be unhelpful and unrealistic; gradually facing activities which may have been avoided; and trying out new ways of behaving and reacting. Relaxation and distraction techniques are also commonly included.
<b>Cognitive behaviour modification</b>	see cognitive behaviour therapy
<b>Cognitive learning strategies</b>	technique used in cognitive behaviour therapy



<b>Cognitive scripts</b>	technique used in cognitive behaviour therapy
<b>Collaborative consultation</b>	a problem solving process that reflects high levels of communication and coordination
<b>Communication partner</b>	the receiver of the message in a communicative exchange
<b>Communication</b>	the act of exchanging or expressing thoughts, feelings and ideas
<b>Co-existing condition</b>	one that exists at the same time as another condition in the same individual
<b>Co-morbid condition</b>	one that exists at the same time as another condition in the same individual. The two conditions are usually independent of each other. For example a child who has autism might also develop leukaemia. That the child has autism complicates treating the leukaemia, but the two conditions are independent of each other.
<b>Consultative model</b>	an integrated process of service provision where the professional works with others (eg, classroom teacher and teacher aide) to achieve outcomes for the child, school or family
<b>Contemporary applied behaviour analysis</b>	the contemporary application of behavioural principles, which holds that conclusions about human development and behaviour should be based on controlled observation of overt behaviour, yet are cognisant of developmental issues
<b>Cooperative teaching/learning</b>	a set of educational practices whereby children of different backgrounds or ability levels work in teams that are structured in such a way that all members have to work together to achieve a common objective or goal
<b>Core deficit</b>	the core deficits in autism spectrum disorders are defined in diagnostic criteria
<b>Cue dependent responding</b>	a situation when specific responses or behaviours in a person's repertoire have come to be dependent on specific stimuli or prompts so that they only occur following these stimuli
<b>Curriculum modification</b>	modifications or alterations to the content, strategies, mode of delivery, and/or expectations to accommodate the needs of the individual
<b>Daily life therapy</b>	see Higashi Schools therapy
<b>Denver Health Sciences Programme</b>	developmentally based programme employing behavioural techniques
<b>Desirable Objectives and Practices (DOPs)</b>	Ministry of Education policy documents for early childhood education services

<b>Developmental coordination disorder</b>	difficulty in the planning and execution of purposeful movements that result in difficulty performing fine and gross motor skills (eg, drawing, buttoning, dressing, learning new motor skills and speech etc). Also known as dyspraxia.
<b>Developmental delay</b>	a delay in one or more areas of language, cognition, motor skills, or other adaptive behaviours
<b>Developmental, Individual Difference, Relationship-based Model (DIR)</b>	type of developmental intervention
<b>Developmental paediatrician</b>	a paediatrician who specialises in the assessment and care of children who have developmental problems or disability
<b>Developmental programmes</b>	programmes which are guided by considerations for the sequence in which children acquire skills and developmental milestones
<b>Developmental services coordinator (DSC)</b>	person appointed to manage the referral process for all children about whom there are developmental concerns
<b>Developmental surveillance</b>	a shared parent/health professional activity which uses both parties' knowledge about the child to monitor development in an ongoing way
<b>Developmentally appropriate practices</b>	activities, materials, curriculum and environment consistent with the developmental stage of the child
<b>Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV)</b>	diagnostic and statistical manual of mental disorders. Now superseded by Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition – Text Revision (DSM-IV-TR)
<b>Differential diagnosis</b>	alternative possible diagnosis. Also commonly used to mean the different diagnostic possibilities which need to be considered in a particular situation
<b>Disability Information Advisory Service (DIAS)</b>	Disability Information Advisory Service
<b>Discrete trial training (DTT)</b>	an intervention based on the principles of applied behaviour analysis. DTT has four distinct parts: the trainer's presentation, the person's response (which may be prompted), the consequence, and a short pause between the consequence and the next instruction.
<b>Distance learning</b>	instruction that is not face-to-face (ie, is by mail or electronic means)
<b>District Health Board (DHB)</b>	District Health Board

<b>Dolman-Delacato method</b>	highly controversial intervention which seeks to repair damage to the brain through the use of ‘patterning’ therapy. This involves a series of bodily exercises that are intended to ‘rewire’ the brain.
<b>Dolphin therapy, or dolphin-assisted therapy</b>	see animal therapy
<b>Dyskinesias</b>	Impairments in the control of ordinary muscle movements. Can be caused by use of some medications especially antipsychotics.
<b>Dyspraxia</b>	difficulty in the planning and execution of purposeful movements that result in difficulty performing fine and gross motor skills (eg, drawing, buttoning, dressing, learning new motor skills and speech etc). Also known as developmental coordination disorder.
<b>EarlyBird</b>	a parent-education programme for parents of young children with autism originally developed in the United Kingdom and now available in New Zealand through Autism New Zealand (jointly funded by the Ministry of Health and Ministry of Education)
<b>Early Intensive Behavioural Intervention</b>	<p>The Living Guideline Group provided this definition following their update on applied behaviour analysis.<sup>12</sup></p> <p>When early, intensive interventions are based on behavioural principles they can be correctly identified as EIBI. There have been many developments in early behavioural intervention since Lovaas first described his protocol in 1987. The common elements of EIBI programmes, paraphrased from Eldevik et al,<sup>432</sup> are as follows:</p> <ul style="list-style-type: none"> <li>(a) intervention is individualised and comprehensive, addressing a range of skills</li> <li>(b) a variety of ABA techniques are used to build new repertoires and reduce interfering behaviour. These are commonly delivered as discrete trial instruction, but may also involve incidental teaching and activity-embedded trials</li> </ul>

<b>Early Intensive Behavioural Intervention</b> (continued)	<ul style="list-style-type: none"> <li>(c) one or more individuals with advanced training in applied behaviour analysis and experience with young children with developmental disabilities (especially ASD) directs (supervises) the programme</li> <li>(d) the selection of intervention goals and short-term objectives is usually guided by understanding of typical developmental sequences</li> <li>(e) parents are encouraged to serve as active co-therapists for their children, and may be trained to do so</li> <li>(f) intervention is delivered in one-to-one fashion initially, with gradual transitions to small-group and large-group formats when warranted</li> <li>(g) intervention typically begins in the home and is carried over into other environments (eg, community settings), with gradual, systematic transitions to preschool, kindergarten, and elementary school classrooms when children develop the skills they are required to learn in those settings</li> <li>(h) programming is intensive, is year round, and includes 20 or more hours of structured sessions per week plus additional informal instruction and practice</li> <li>(i) in those programmes that have been formally evaluated, the duration of intervention is usually 2 or more years</li> <li>(j) the intervention programme is usually commenced in the preschool years, when the children are 3 to 4 years of age.</li> </ul>
<b>Echolalia</b>	the repetition of speech produced by others. The echoed words or phrases can include the same words and exact inflections as originally heard, or they may be slightly modified. Immediate echolalia refers to echoed words spoken immediately or a very brief time after they were heard. Delayed echolalia refers to echoed 'tapes' that are repeated at a much later time – days or even years later.
<b>Eclectic approach</b>	a teaching approach which draws on elements from many theoretical models
<b>Eco-cultural</b>	the ecology of the social and cultural influences surrounding the child and family/whānau
<b>Ecological approach/model</b>	an ecological approach or model is a view, practice or orientation that considers the role the environment plays in development, learning and behaviour. For example, ecological assessments would include the study of the child in his/her physical, social and learning environments.

<b>Electroencephalogram (EEG)</b>	a recording of the changes in electric potential associated with activity of the cerebral cortex. EEG is used in the evaluation of epilepsy.
<b>Empathy</b>	identification with and understanding of another's situation, feelings, and motives
<b>Empirically validated strategies</b>	strategies for which there is research evidence
<b>Engagement</b>	refers to the amount of time that a child is attending to and actively participating in the social and non-social environment
<b>Enuresis</b>	incontinence, the involuntary passing of urine. 'Nocturnal enuresis' refers to bedwetting.
<b>Environmental barriers</b>	aspects of the environment which limit access to full inclusion and participation. Aspects of the environment are identified as natural environment, built environment, support and relationships, attitudes, services/systems/policies, equipment/products and technology.
<b>Environmental modification/adaption</b>	making changes to the environment to facilitate safety, to make care easier, to support behaviour change or to make the person more comfortable. For example, provision of a safe fenced area by installing climb-proof fencing; installation of Perspex windows to prevent injury from broken glass; moving breakable ornaments out of reach of a child; removing seasonal clothing to support appropriate dress for conditions; addressing noise or other sensory factors.
<b>Epidemiology</b>	the study of how a disease affects a population, ie, incidence, control, distribution etc
<b>Epistaxis</b>	nosebleed
<b>Executive function</b>	the self-organisational elements required to learn or behave. In neuropsychology and cognitive psychology, 'executive functioning' is the mental capacity to control and purposefully apply one's own mental skills. Different executive functions may include: the ability to sustain or flexibly redirect attention, the inhibition of inappropriate behavioural or emotional responses, the planning of strategies for future behaviour, the initiation and execution of these strategies and the ability to flexibly switch among problem-solving strategies. Current research evidence suggests that executive functioning in the human brain is mediated by the prefrontal lobes of the cerebral cortex.

<b>Expressive communication</b>	the process by which a person sends information in messages to other people. Includes the process of understanding the purpose of communicating as well as functions such as using verbal or non-verbal communication.
<b>Expressive language</b>	sending information or messages to other people using verbal or non-verbal language
<b>Extrapyramidal symptoms</b>	neurological symptoms including tremors, muscle rigidity, a shuffling gait, restlessness, and difficulty initiating movement
<b>Eye contact</b>	the event when two people's gaze meets. The skill of looking at their communication partner or making eye contact has been traditionally assessed as evidence that individuals are attending or have joint attention.
<b>Evidence-based recommendations</b>	recommendations that are supported by evidence from a systematic review of the literature.
<b>Facilitated communication (FC)</b>	technique used for people with communication difficulties whereby they are supported to point to or touch objects, letters, symbols or pictures
<b>False memory</b>	memory of an event that did not happen or is a distortion of an event that did occur as determined by externally corroborated facts
<b>Family-centred services</b>	services, goals and plans for a child that are based on family needs and preferences
<b>Family Care Plan (FCP)</b>	a support plan to meet the individual needs of children and their families, usually around early intervention services
<b>Floor Time</b>	therapy provided by the Floortime Foundation, which describes it as meeting a child at his current developmental level and building on his/her particular set of strengths
<b>Formulation</b>	the process of integrating assessment information systematically
<b>Fragile X</b>	a single gene disorder causing intellectual disability, and autistic and hyperactive behaviour in males. Females usually have more subtle learning difficulties and often have problems with social anxiety.
<b>Functional alternative</b>	a behaviour that serves the same function as a current challenging behaviour. Teaching functional alternative behaviours helps to eliminate the undesirable behaviour by reducing the need for it.

<b>Functional analysis</b>	<p>determining the possible cause of inappropriate behaviour, through a process of observation, data collection and the systematic manipulation of variables. Used to identify intervention strategies.</p> <p>Functional analysis is based on the notion that all behaviour serves a function for the individual concerned. If the function of a specific undesirable behaviour is known, then an appropriate functional alternative can be taught, and undesirable behaviour eliminated by ensuring that it functions as well as the appropriate alternative.</p>
<b>Functional assessment</b>	the observation phase of functional analysis. Sometimes referred to as 'functional behaviour assessment'.
<b>Functional communication</b>	how the child communicates in their everyday environments which may include a range of communication forms, eg, signs, gestures, visual symbols or language
<b>Functional communication training</b>	is often part of an intervention where a problem behaviour serves a communicative function. Acceptable functional alternatives to the problem behaviour are taught so that the child is able to communicate appropriately.
<b>Functionality</b>	likely to be useful – giving access to control of the child or young person's environment, increasing independence and quality of life, increasing competence of performance
<b>Further education</b>	tertiary education (university or polytechnic), adult education, and vocational training schemes
<b>Gastrointestinal problems</b>	<p>refer to dysfunction that is evident in clinical symptoms, usually chronic, persistent, recurrent, frequent or excessive in nature, which do not have clear anatomic, metabolic, or pathologic process. These problems may include the following:</p> <ul style="list-style-type: none"> <li>• chronic constipation</li> <li>• diarrhoea, faecal incontinence, encopresis (faecal soiling); changes to bowel habit</li> <li>• vomiting, nausea, gastroesophageal reflux (GER)</li> <li>• abdominal pain, discomfort, irritability, bloating; flatulence.</li> </ul>
<b>Generalisation</b>	transfer of learning. When behaviour learned in a certain setting or in the presence of a certain stimulus occurs in other similar settings or in the presence of other similar stimuli. Also known as 'stimulus generalisation'.

<b>General paediatrician</b>	a specialist paediatrician who provides health care to children who have a range of different problems, including, for example, developmental problems or respiratory problems such as asthma. Most paediatricians in New Zealand are general paediatricians.
<b>Gentle teaching</b>	non-violent approach for helping people with special needs and sometimes challenging behaviours
<b>Gluten-casein free diet</b>	a diet which contains no gluten (a protein found in many cereals such as wheat) and no casein (a protein found in milk)
<b>GSE</b>	Ministry of Education, Special Education
<b>Health care professionals (HCPs)</b>	an umbrella term for all professionals working in the health care field. It includes doctors, nurses, physiotherapists etc.
<b>Hidden curriculum</b>	skills which are not generally explicitly taught, but which most people understand such as the different social rules to apply to different people (peers, parents, teachers etc)
<b>Higashi Schools therapy</b>	therapy which uses group dynamics, physical education, art, music, academic activity and vocational training. Also known as Higashi.
<b>High functioning autism (HFA)</b>	those people with autism without any intellectual impairment, who do not meet the diagnostic criteria for Asperger syndrome because they had significantly delayed language development, even though their current language ability may be average to high
<b>Holding therapy</b>	forced holding by a therapist or parent until the child stops resisting or until a fixed period has elapsed
<b>Hyperactivity</b>	continual, inappropriate motor activity
<b>Hyperarousal</b>	a state of excessive arousal or wakefulness
<b>Hyperlexia</b>	being able to read words beyond what would be predicted based on cognitive and language scores and the early (age 2–5), compulsive, or indiscriminate reading of words that has developed in the absence of direct instruction
<b>Hyperprolactinaemia</b>	excess secretion of the hormone prolactin
<b>Hypersensitivities</b>	acute, often painful physical sensation or reaction to sensory input due to over responsivity of sensory systems
<b>International Classification of Diseases, version 10 (ICD-10)</b>	International Classification of Diseases, version 10
<b>Ideation</b>	thinking



<b>Incidence</b>	rate of occurrence of new cases of a particular disease or condition in a population
<b>Incidental teaching</b>	systematic instruction which is delivered in the context of natural routines and play activities in everyday environments
<b>Inclusion</b>	refers to the philosophy, policy and practice of providing participation and learning opportunities for all children according to their needs
<b>Inclusive settings</b>	home, community and educational settings where children are valued and engaged with their age peers, family, whānau and community members in everyday life experiences based on family, social and cultural choices
<b>Individual Education Programme (IEP)</b>	the individual planning process which is the basis of collaborative planning between home, school and specialist services. Goals are based on the New Zealand curriculum.
<b>Individual (Development) Plan (IP or IDP)</b>	a plan which is sometimes used in early childhood education services. Goals are based on Te Whāriki, the early childhood education curriculum.
<b>Individual profile</b>	information about the child such as preferred modes of communication, reinforcer preferences and dislikes, sensory responses and preferred learning modes. The information is supplied by the group of people who know the child best.
<b>Insight-oriented therapy</b>	various forms of psychotherapy which draw on the premise that emotional problems are the result of unconscious psychological conflicts and that improvement occurs when clients develop insight into these conflicts
<b>Intellectual disability</b>	a condition manifested before the age of 18, in which people have both significantly subaverage intellectual functioning, and significant deficits in adaptive function
<b>Intensity</b>	‘dose’ of ‘treatment’ in an intervention programme
<b>Intervention</b>	any action which is designed to bring about change, eg, changing where a child sits, providing a particular reinforcement, providing a picture schedule
<b>Irlen lenses</b>	lenses prescribed and supplied by the Irlen Institute and others to alleviate symptoms of Scotopic Sensitivity Syndrome
<b>Islets of ability</b>	see savant skills
<b>Joint attention</b>	where two individuals (usually a child and caregiver) coordinate their attention about an object of mutual interest. This involves shifting their attentions from each other to an object and back again.
<b>Joint attention routines</b>	technique used in applied behaviour analysis and some other interventions

<b>Karyotype</b>	the analysis of an individual's complement of chromosomes
<b>Kanner type ASD</b>	also sometimes referred to as 'core autism' and used to describe those individuals most similar to the group of children described by Leo Kanner in 1943. These individuals are at the severe end of the ASD spectrum.
<b>Key worker</b>	a person who may be nominated by a team of professionals from one agency who is working with a child, individual or family. The key worker then acts as a first point of contact for the individual with ASD or family and for other agencies who are also involved.
<b>Lability</b>	readily or frequently undergoing change (lability of mood refers to fast and frequent mood changes)
<b>Language</b>	( <i>see communication</i> ) a rule-based form of communication, eg, verbal and written language
<b>Learning Experiences: An Alternative Programme for Preschoolers and Parents (LEAP)</b>	intervention in which very young children with autism are taught alongside ordinary children
<b>Learning Stories</b>	form of narrative assessment (often used by early childhood teachers)
<b>Least restrictive environment</b>	is a mandate or requirement in the United States. It means that each child should be accommodated in the least restrictive setting (ie, as close to a mainstream setting as possible) required to still meet that student's needs. A more restrictive environment may be required for students with severe behavioural needs, such that they represent a danger to themselves or others.
<b>Lovaas Method</b>	programme of applied behaviour analysis developed by Dr O. I. Lovaas. Also known as Young Autism Project and Early Intensive Behavioural Intervention.
<b>Magnetic resonance imaging (MRI)</b>	a form of medical imaging which uses a strong electromagnet. It provides detailed pictures of the structure of the body or the brain.
<b>Maintenance</b>	evidence that the behaviour change has continued over a period
<b>Mentoring</b>	the practice of assigning a person to a more experienced person to provide advice or guidance
<b>Mind map</b>	visual aid to show a logical sequence of ideas
<b>Mindblindness</b>	impairment or deficit in a person's 'theory of mind' ( <i>see theory of mind</i> )

<b>MMR</b>	a vaccine containing modified live viruses to protect against infection with the diseases measles, mumps and rubella (german measles).
<b>Mnemonic device</b>	aid such as a verse or acronym to aid one's memory
<b>Model</b>	the theoretical base or description of a programme or intervention, eg, behavioural or developmental model
<b>Motivation</b>	a stimulus to action; something (a need or desire) that causes one to act
<b>Motor Skills</b>	skilled performance of motor tasks (eg, walk, tie up laces, write etc). Motor skills are often further divided into fine and gross motor skills and are reliant on complex interrelation of neurological, physiological and individual factors.
<b>Multiagency</b>	involving two or more agencies or personnel from two or more agencies
<b>Multidisciplinary team</b>	professionals who have a range of skills and develop their own goals and intervention plans
<b>Music therapy</b>	using music as a tool for communication or as nonverbal symbolic means of expression
<b>Narrative assessment</b>	using narrative as a way of assessing children's learning, for example, learning stories
<b>Natural contexts</b>	the settings, people and equipment that would be associated with everyday activities
<b>Natural settings</b>	the usual settings that would be associated with everyday activities. For example, teaching about shopping in a supermarket rather than a classroom.
<b>Naturalistic teaching</b>	using natural contexts to teach skills
<b>Needs Assessment and Service Coordination (NASC)</b>	Needs Assessment and Service Coordination
<b>Negative Reinforcement</b>	occurs when a behaviour (response) is followed by the removal of an aversive (unpleasant) stimulus. The word 'reinforcement' is defined by the effect it has on behaviour, which is to increase the likelihood of the behaviour to occur in the future. The word 'negative' signals that this is achieved by withdrawing something. Because the situation becomes more pleasant for the individual as a result of negative reinforcement the effect is to strengthen the behaviour or response it follows.
<b>Neuro-biological</b>	the biology or science of the nervous system

<b>Neurotoxicity</b>	effects of a substance (eg, a medication or chemical) which is toxic or damaging to the brain or nervous system or both
<b>Neurotransmitter</b>	the chemical messenger which plays a part in the transmission of messages from one neuron or nerve cell to another
<b>Neurotypical (NT)</b>	neurologically typical. A word (often used by individuals with autism) to describe neurologically typical (or not autistic) individuals.
<b>New Zealand Association of Occupational Therapists (NZAOT)</b>	professional association of occupational therapists
<b>New Zealand Health Technology Assessment (NZHTA)</b>	New Zealand Health Technology Assessment, a clearing house for health outcomes and health technology assessment based at the University of Otago, New Zealand.
<b>NGO</b>	non-governmental organisation
<b>Non-verbal communication</b>	any form of communication that does not involve the use of spoken language, eg, gestures
<b>Obsessive-compulsive disorder (OCD)</b>	a psychiatric anxiety disorder most commonly characterised by a subject's obsessive, distressing, intrusive thoughts and related compulsions (tasks or 'rituals') which attempt to neutralise the obsessions
<b>Occupational therapist (OT)</b>	therapist trained to enable people to participate in daily activities as independently and satisfactorily as possible, using meaningful activities as a means to do this
<b>Off-label</b>	describes the prescription of a drug outside the manufacturer's recommendations for that drug
<b>Ongoing and Reviewable Resourcing Schemes (ORRS)</b>	Ongoing and Reviewable Resourcing Schemes provide resources for a very small group of school students throughout New Zealand who have the highest need for special education. Most of these students have this level of need throughout their school years.
<b>Options method</b>	see Son-Rise
<b>Over-selectivity</b>	the trend to respond only to part of a stimulus rather than the whole object or to the whole social setting
<b>Paradoxical responses to stimuli</b>	unexpected reactions to sensory input
<b>Paraprofessional</b>	person who supplements or supports the work of a professional such as a teacher, eg, teacher's aide, support worker

<b>Parent-managed applied behaviour analysis</b>	behavioural intervention developed and implemented by parent with limited training
<b>Patterning</b>	range of therapies which use a series of bodily exercises and other activities which are intended to 'rewire' the brain
<b>Peer-mediated techniques</b>	interventions using peers as co-therapists, or including peers as tutors or teachers
<b>Peer tutoring</b>	using the child's peers as tutors or teachers
<b>Perceptual distortions</b>	distortions of the visual senses, programme difficulties in looking at print
<b>Perceptual organisation</b>	assessment of the process of 'thinking', including perception, reasoning, problem solving and memory
<b>Periodontitis</b>	inflammation of the tissue surrounding the neck and root of a tooth
<b>Perseveration</b>	repetitive movement or speech, or sticking to an idea or task, that has a compulsive quality to it
<b>Perseverative behaviour</b>	engaging in Perseveration ( <i>see above</i> )
<b>Person-centred planning</b>	covers a number of approaches that assess and review the needs of disabled people within a community setting, which actively involve the person with disabilities as the 'focus' person, and includes their chosen main carers and friends
<b>Pervasive Developmental Disorder (PDD)</b>	another term for autism spectrum disorder
<b>Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)</b>	a form of ASD or PDD in which an individual does not meet the criteria for other forms of ASD, such as autism or Asperger syndrome
<b>Pet therapy</b>	see animal therapy
<b>Pharmacotherapy</b>	the use of medications or drugs to treat disease
<b>Pharmacodynamics</b>	the science of the action of drugs
<b>Pharmacokinetics</b>	the study of the way a particular drug behaves in the body, eg, how rapidly it is absorbed and how quickly it is broken down by the body
<b>Phenotype</b>	the visible characteristics or traits which characterise an individual or a group of individuals

<b>Physiotherapy</b>	assessment and treatment interventions conducted by a physiotherapist, eg, exercise, adaptations to support physical participation in the curriculum
<b>Picture Exchange Communication System (PECS)</b>	an augmentative communication training package (developed by Andrew S. Bondy and Lori Frost) that teaches children and adults with autism and other communication deficits to initiate communication. PECS developed from applied behaviour analysis.
<b>Pivotal response training (PRT)</b>	a technique targeting pivotal skills (motivation, self-management, and initiating interactions, for example) that are expected to be associated with wider behaviour change (developed by Robert and Lynn Koegel at the Autism Research Centre, University of California)
<b>Pivotal skills</b>	skills deemed to be pivotal or central in a child's development. Targeting pivotal skills is expected to lead to broader changes including in non-targeted behaviours. They describe large areas of general functioning such communication, motivation or self-management.
<b>Play dates</b>	social opportunities with peers usually conducted within the home
<b>Play-oriented strategies</b>	the use of play to achieve learning goals
<b>Play therapy</b>	therapy in which play is used to help individuals to address and resolve their own problems
<b>Plunket</b>	the Royal New Zealand Plunket Society is a not-for-profit organisation founded in 1907 with the goal of supporting and educating mothers of infants and children. Today it is the major provider of Well Child/Tamariki Ora services in New Zealand.
<b>Positive behavioural approaches</b>	behavioural approaches that promote adaptive, socially meaningful behaviours, help overcome maladaptive behaviours and avoid the use of punishment. The primary goal of positive behavioural supports is to teach functional skills as a replacement for problem behaviour. Positive behavioural support typically involves changing existing environments in a manner that makes problem behaviours irrelevant, ineffective and inefficient.

<b>Positive reinforcement</b>	occurs when a behaviour (response) is followed by a desirable or pleasant stimulus that increases the frequency of that behaviour. The word 'reinforcement' is defined by the effect it has on behaviour, which is to increase the likelihood of the behaviour to occur in the future. The word 'positive' signals that this is achieved by adding something. Because the situation becomes more pleasant for the individual as a result of positive reinforcement the effect is to strengthen the behaviour or response it follows.
<b>Power cards</b>	cards which an individual carries to remind him or her how to deal with a difficult situation
<b>Pragmatic (aspects of communication)</b>	the practical aspects communicating in natural settings, for examples social rules about eye contact, taking turns, observing body language, selecting topics of conversation etc.
<b>Pre-linguistic communication</b>	communication features such as joint attention, gesture, eye contact, vocalisations etc that form the basis of expression prior to spoken language development
<b>Prevalence</b>	percentage of a population that is affected with a particular disease or condition at a given time
<b>Priapism</b>	persistent and painful erection of the penis
<b>Programme</b>	a particular service with carefully planned steps, eg, CARD or LEAP
<b>Prompt-dependent</b>	an individual can only perform an action following the prompt that was associated with the learning. The learning has not been generalised.
<b>Prompt (verbal, physical)</b>	a cue or hint (picture, words, touch) meant to induce a person to perform a desired behaviour
<b>Proprioception</b>	the perception of sensations coming from joints, muscles, tendons and ligaments that allow the brain to know where each body part is and how it is moving
<b>Prosody</b>	the variation of tone in spoken language
<b>Psychodynamic therapy</b>	psychological therapy based on the teaching of Sigmund Freud and neo-Freudists
<b>Psychological hardiness</b>	resilience, the ability to 'survive' or maintain adaptive function despite major stressors or challenges
<b>Psychometric</b>	the measurement of mental and psychological ability, potential and performance, especially measurement of intelligence
<b>Psychosocial</b>	relating to both psychological and social factors
<b>Psychotherapy</b>	the treatment of mental disorders by psychological methods

<b>Psychotropic</b>	relating to a medication or drug that has an effect on the individual's psychological functioning or behaviour
<b>Randomised controlled trial (RCT)</b>	an experiment in which two or more interventions, possibly including a control intervention or no intervention, are compared by being randomly allocated to participants
<b>Receptive communication</b>	the understanding of that which is said, written or signed
<b>Receptor antagonist</b>	a binding partner of a receptor (molecular structure or site on the surface or interior of a cell) that inhibits the function of an agonist by blocking its binding to the receptor. An agonist combines with a receptor on a cell to produce an action and the antagonist prevents that action.
<b>Recovery</b>	the child no longer meeting any of the diagnostic criteria for Autism Spectrum Disorders
<b>Regional Intellectual Disability Care Agency (RIDCA)</b>	Regional Intellectual Disability Care Agency
<b>Regional Intellectual Disability Supported Accommodation Services (RIDSAS)</b>	Regional Intellectual Disability Supported Accommodation Services
<b>Reinforcement</b>	any event, stimulus, or behaviour which, when made contingent on a response, serves to increase the frequency or likelihood of occurrence of that response
<b>Reinforcer</b>	any event or behaviour that results in 'reinforcing' or strengthening the behaviour it follows. Reinforcers increase the likelihood of the behaviour occurring again in the future.
<b>Relationship development intervention (RDI)</b>	intervention which aims to develop an individual's ability to participate in authentic emotional relationships by exposing the individual to those relationships in a gradual, systematic way
<b>Repetitive behaviour</b>	repeating the same behaviour over and over, eg, rocking for hours
<b>Resource Teacher of Learning and Behaviour (RTLb)</b>	itinerant consultant in the New Zealand school system whose role is to assist teachers in better catering for students with mild to moderate behaviour or learning needs within regular schools
<b>Respite care</b>	skilled adult supervision to give primary carers an opportunity for relief from the demands of caregiving



<b>Rett syndrome</b>	a syndrome, seen mainly in girls, who characteristically show normal early development in the first few months of life, followed by a period of withdrawal and loss of skills (such as hand function, social engagement, gait and trunk movements and severely impaired expressive and receptive language development). Girls with Rett syndrome may be diagnosed with ASD, before the full picture of the syndrome becomes evident. Rett syndrome is now known to be due to a defect in a gene on the X chromosome. The understanding of the clinical picture in Rett is still developing.
<b>Role play</b>	acting out of a role as a means of practising a response
<b>Rote drill</b>	repeated learning or drilling of facts (such as times tables)
<b>Round (or length of round)</b>	the quantity of information in one 'turn' of an interaction between individuals
<b>Savant skills</b>	an individual with autism who may have exceptional skills in a particular area
<b>Scaffolding</b>	supporting learning
<b>Scotopic sensitivity syndrome</b>	condition in which individuals are especially sensitive to lights, glare, patterns, colours, and contrast. See Irlen lenses
<b>Scripts</b>	using written narratives to teach appropriate skills, eg, going to the library
<b>Script fading</b>	gradually using less information in the scripts until the skills can be used without the script
<b>Segregated settings</b>	environments in which children are separated from their (typically developing) peers for reasons relating to their disability or diagnosis
<b>Self-injury</b>	self-inflicted injury to oneself, usually in response to stress or anxiety. It can involve hitting one's face, gouging one's eyes, gouging or cutting the skin or head banging.
<b>Selective serotonin re-uptake inhibitor (SSRI)</b>	an antidepressant medication
<b>Self-stimulatory behaviour</b>	(also known as <i>stimming</i> ), also known as self-stimulation – a term for behaviours whose purpose appears to stimulate one's senses. Many people with autism report that some self-stimulation may serve a regulatory purpose (ie, calming, increasing concentration or shutting out overwhelming sensory input).
<b>Semantic</b>	relating to the meaning of language

<b>Sensory impairment</b>	deficit in sensory function (eg, reduced visual acuity secondary to a primary eye abnormality or to damage of the visual cortex or impaired hearing or any other sensory deficit). Impaired sensory processing functions can affect learning, play, work, socialisation, health and wellbeing.
<b>Sensory integration</b>	a theory of brain behaviour relationship which explores the organisation of sensory input in order that individuals can effectively interact with the environment by making adaptive responses
<b>Sensory modulation</b>	ongoing physiological process central to the ability to filter or attend selectively to sensory information
<b>Sensory-motor handling</b>	a broad range of unrelated treatment techniques focusing on the sensory or motor systems, eg, reflex integration, neuro-developmental therapies, patterning etc
<b>Sensory overload or defensiveness</b>	a group of symptoms that show over-reactions to sensory input. Individuals may show avoidance, seeking, fear, anxiety and even aggression in reaction to sensory stimuli, particularly if they are over-exposed to them.
<b>Sensory stimulation</b>	sounds, smells, tactile sensations and other inputs which stimulate the senses
<b>Serotonin</b>	a neurotransmitter involved in, for example, sleep and depression and memory
<b>Severe and complex behaviour</b>	see challenging behaviour
<b>Shared positive affect</b>	positive or pleasurable shared experiences between children and others
<b>Sialorrhoea</b>	excessive production of saliva; drooling
<b>Sibkids</b>	online support group for siblings
<b>Social communication</b>	the skills that allow people to interact with and influence others and gain some control over the environment
<b>Social Communication Emotional Regulation Transactional Supports (SCERTS™)</b>	multidisciplinary educational intervention that focuses on the development of spontaneous communication, teaching and supporting the child to regulate his or her emotional state and providing supports to the child, the family and the professionals working with the child
<b>Social decision-making strategies</b>	curriculum-based programme that targets self-control and social awareness skills, teaches an eight-step social decision-making strategy and incorporates practicing the skills in real life situations

<b>Social model of disability</b>	a model that describes disabling social, environmental and attitudinal barriers that people with disabilities face, rather than lack of ability on the part of the individual
<b>Social skill repertoire</b>	the set of social skills (positive appropriate social behaviours) that an individual possesses
<b>Social skills groups</b>	interventions which provide structured sessions in social skills training in small groups of people of a similar age group and with similar social problems. A session typically includes teaching a specific skill, demonstration of the skill through role playing, practice of the skill, and individualised feedback. Groups meet on a regular basis, typically for 1-2 hours, for several weeks, facilitated by at least one trained instructor/therapist. Parents are typically provided training in concurrent sessions to encourage their children to practice newly learned skills at home.
<b>Social stories</b>	narratives written about social situations to assist understanding, to help the person manage their anxiety and sometimes to encourage appropriate behaviour
<b>Social validity</b>	a skill or behaviour is said to have social validity if it leads to increased adaptive action alternatives for the individual such that he/she is likely to have access to more reinforcements, or is able to have better life circumstance/experiences, ie, that meets a practical or social need for this child and their family
<b>Son-Rise</b>	intensive training programme based on the idea that the best way to help a child with autism is to follow the child's lead. Also known as the Options method.
<b>Special Education Needs Coordinator (SENCO)</b>	a person in schools who coordinates programmes for children with special education needs
<b>Specialised curriculum</b>	a curriculum which is tailored to meet the needs of the child with ASD. Such a curriculum usually emphasises social and communication skills.
<b>Speech</b>	the act of speaking (or using verbal language)
<b>Speech-language therapist (SLT)</b>	therapist trained to work with individuals to help them develop their communication skills using a range of techniques
<b>Splinter skills</b>	see savant skills
<b>Spontaneous communication</b>	unprompted communication
<b>Stereotypies</b>	persistent postural, gestural or verbal responses that are without apparent meaning and tend to recur inappropriately
<b>Stimming</b>	see self-stimulatory behaviours

<b>Structure</b>	environments or activities can be structured, and this will increase clarity and predictability, and make it easier for people to negotiate their way around them successfully. When the curriculum or the expectations (activities, schedule and environment) are clear and comprehensible and predictable to both the students and observers.
<b>Structured environments</b>	environments which are planned to ensure that students have a clear comprehensible programme and environment
<b>Supported employment</b>	<p>formal programmes providing ongoing support (flexible, individualised, for an indefinite time) to find and maintain real paid work (paid at no less than market pay rates and under standard conditions) in ‘integrated’ settings alongside people without disabilities. In some conventions, minimum hours of employment may be specified (eg, at least 16 hours per week) or minimum periods of employment. Less comprehensive forms of assistance which do not provide ongoing on-the-job support are termed <i>employment supports</i>. Employment supports, and more specifically supported employment, can be offered by employment services as described in the guideline.</p> <p>Supported employment is to be distinguished from <i>sheltered employment</i> where people work alongside other people with disabilities in a segregated, specially tailored settings and are commonly paid below market-rate wages.</p>
<b>Symbolic or dramatic play</b>	involves the use of pretence or the deliberate misrepresentation of reality, as in pretending to eat a non-existent cookie or using a block as if it were a truck
<b>Symptom substitution</b>	where an individual learns to eliminate one behaviour, but substitutes another behaviour to get the same gain
<b>Systematic instruction</b>	planned, explicit, intentional teaching based on thorough assessments
<b>Tactile</b>	relating to the sense of touch
<b>Tactile defensiveness</b>	hypersensitivity to senses of touch
<b>Tardive</b>	characterised by tardiness, lateness. Used of diseases and disorders in which characteristic symptoms appear relatively late in the normal course of the disorder.
<b>Tardive dyskinesia</b>	a movement disorder consisting of repetitive, involuntary, purposeless movements, resulting from the use of antipsychotic medications. Effects may be permanent and continue after medication has stopped.
<b>Task analysis</b>	analysing a task to identify the individual elements

<b>Task organiser</b>	breaking a task into small steps which are presented in written or visual form
<b>TEACCH (Treatment and education of autistic and related communication-handicapped children)</b>	a structured teaching intervention developed by Division TEACCH, part of the Department of Psychiatry at the School of Medicine, University of North Carolina in the USA
<b>Theory of mind (ToM)</b>	the ability to identify the mental states of oneself and others and to understand that others have desires and intentions that are different from one's own
<b>Tic</b>	a habitual stereotyped movement or complex of movements. The individual is aware of the movement but is unable to prevent the movement from happening.
<b>Time-out (from reinforcement)</b>	a behavioural strategy whereby a child is removed from their usual environment. In autism, can also be used to describe giving the child 'down time' to assist with anxiety and stress.
<b>Tourette syndrome</b>	a disorder of the nervous system characterised by repeated involuntary movements and uncontrollable vocal sounds called tics. In a few patients, such tics can include inappropriate words and phrases.
<b>Transition</b>	movement between activities or environments. These can be major transitions or daily transitions. Examples of major transitions include movement from early childhood education settings/day care to school, between schools, and from school into work, vocational services or further education. Examples of daily transitions include movement from house to car, lino to carpet, entering another space, changes to new living environment, going to bed.
<b>Trial teaching</b>	using assessment to determine a child's rate of learning using particular strategies during a trial period
<b>Tuberose sclerosis</b>	a disorder associated with autistic behaviour. It is characterised by typical skin lesions and often associated with epilepsy. It is inherited as an autosomal dominant trait, but a substantial proportion of cases represent new mutations.
<b>Typically developing peers</b>	children whose development is following the expected path
<b>Twilight time</b>	(in relation to teachers) the time after school or in the evening
<b>Vestibular</b>	the sensory system that responds to the position of head and body movement and coordinates movements of the eyes, head and body. Receptors are located in the inner ear.

<b>Video modelling</b>	using video to model or convey meaningful information. This is also a specific strategy where videos are constructed of the individual in question performing an action correctly.
<b>Visual (cuing, supports, symbols)</b>	written, pictorial or photographic schedules, lists, sequence supports that convey meaningful information in a permanent format for later reference. The purpose of such supports is to allow individuals with autism to function more independently without constant verbal directions.
<b>Visual therapy</b>	therapy which aims to improve visual processing or visual spatial perception
<b>Visual-spatial skills</b>	cognitive abilities that relate to the way people perceive the objects and surroundings of their environment
<b>Vocational services</b>	employment services, or services which find or provide meaningful daytime activities
<b>Well Child/Tamariki Ora</b>	The Well Child/Tamariki Ora Framework covers screening, education and support services offered to all New Zealand children, from birth to five years, and to their families/whānau. Well Child services encompass health education and promotion, health protection and clinical support, and family/whānau support. They also ensure that parents are linked to other early childhood services, such as early childhood education and social support services, if required. Providers of Well Child services include registered nurses and community health workers/kaiawhina who have specific training in child health ( <i>see also Tamariki Ora in Glossary of Māori and Pacific Terms</i> ).
<b>Young Autism Project</b>	see Lovaas method

## Glossary of Māori and Pacific terms

<b>Aroha</b>	love in its broadest sense
<b>Fono</b>	to gather together; have a meeting
<b>Haka</b>	fierce rhythmical dance
<b>Hui</b>	a gathering following Māori protocols
<b>Iwi</b>	tribe, bone, people
<b>Kai</b>	food
<b>Kaiarahi</b>	guide
<b>Kaiawhina</b>	support person
<b>Kanohi ki te kanohi</b>	face-to-face communication
<b>Karakia</b>	prayer, ritual chant
<b>Karanga</b>	ritual call of arrival and welcome
<b>Kaumātua</b>	respected elder (men and women)
<b>Kaupapa</b>	purpose
<b>Kawa</b>	protocol, procedure
<b>Kōhanga reo</b>	Māori-medium early childhood education centre
<b>Kuia</b>	respected female elder
<b>Kura kaupapa Māori</b>	Māori medium school based on Māori practices and philosophies
<b>Manaaki</b>	care for, provide support in a respectful manner
<b>Mana atua</b>	wellbeing
<b>Mana aotūroa</b>	exploration
<b>Mana reo</b>	observing the local language of the region
<b>Mana tangata</b>	people upholding the prestige of the local area
<b>Mana whenua</b>	tribal people of the local area
<b>Marae</b>	cultural meeting ground or place
<b>Mihi</b>	greet, introduction
<b>Poi</b>	swinging ball used in a traditional dance
<b>Pono</b>	truth, a validity principle
<b>Pōwhiri</b>	formal welcoming ceremony
<b>Raranga</b>	weaving
<b>Rūnanga</b>	regional Māori council

<b>Taiaha</b>	long-handled, two-handed weapon used in traditional Māori martial art form
<b>Tamariki Ora</b>	Well Child – a national schedule of services that provide ‘well child’ care, including screening, surveillance, education and support services to all New Zealand children from birth to five years and their family or whānau
<b>Tapu</b>	sacred
<b>Te reo Māori</b>	the Māori language
<b>Te Whāriki</b>	the New Zealand early childhood curriculum
<b>Te Whare Tapa Whā</b>	framework of Māori health (four-sided house)
<b>Tika</b>	authentic, observing custom
<b>Tikanga</b>	customs, protocol, rules, principles
<b>Tohunga</b>	expert
<b>Waiata</b>	song
<b>Waka-ama</b>	outrigger canoe paddling
<b>Wānanga</b>	discussion, place of learning
<b>Whakamā</b>	shy, embarrassed
<b>Whānau</b>	extended family
<b>Whanaungatanga</b>	kinship, relationship



## Appendices

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

## Appendix 1: ASD Guideline development process

The development of the ASD Guideline was initially based on a phased approach where the work was discretely divided amongst three separate workstreams into age bands. This framework was later set aside in 2004 in favour of a more flexible, collaborative, ‘whole of life’ way of working across all workstreams.

### Workstream input

The workstreams were established to cover the main components of the ASD Guideline.

1. The Paediatric Society led the Assessment and Diagnosis workstream, formerly known as the Early Intervention workstream, which was established in November 2002. This workstream covered:

- definitions and prevalence rates
- diagnosing ASD in children
- assessment and assessment pathways
- the role of diagnostic and screening tools
- pharmacotherapy for children.

2. The Ministry of Education, Special Education (GSE) led the Education workstream, which commenced work in March 2003. This workstream covered:

- support for families’ involvement in education
- the implications for teaching and learning arising from the child and adolescent’s communication, cognitive, social and sensory characteristics
- early intervention approaches and the framework of the Te Whāriki curriculum

- teaching and management strategies and the key curriculum areas for students with ASD
- professional learning and development for professionals working in education.

3. The Disability Services Directorate in the Ministry of Health led the Support and Transition workstream, which commenced in April 2004. This workstream covered:

- assessment and diagnosis of young people and adults
- Needs Assessment and Service Coordination
- supported and independent living options
- physical wellbeing
- employment and adult education
- recreation and leisure
- behavioural, emotional and mental health difficulties
- contact with the police, courts and criminal justice system
- the needs of others.

In March 2004 a Technical Advisory Group was developed. This group consisted of up to two representatives from each of the three workstreams and the project manager. At specific times during the development of the guideline, expert advisors were also co-opted on to the group, including a NZGG representative and technical editors.

## Māori input

Although Māori perspectives had been incorporated into some of the guideline development processes, the workstream leaders and Ministries of Education and Health identified the need for a more focused and specific Māori input.

A Māori Advisory Group was formed in 2004 and consisted of Māori health, education and disability representatives who also had knowledge of ASD. Following advice from the Māori Advisory Group, work was undertaken to identify points within the existing guideline material where Māori-specific information or commentary would be required. These signposts or themes were used during the five ASD hui held in November 2005 to gain further Māori input.

More than 150 predominately Māori professionals, service providers, parents and whānau attended the hui and provided feedback for the development of the New Zealand ASD Guideline. The feedback from the hui was analysed and incorporated with other Māori research and information into the section of the guideline on Māori perspectives.

## Pacific peoples' input

In 2004, a fono was held to discuss how Pacific ASD-related needs could be addressed in the guideline. A range of different perspectives was gathered and a report was produced to summarise the findings of the fono. This information was then developed into a section of the guideline on Pacific peoples' perspectives.

## Consultation

The detailed development of the guideline was undertaken by small working groups within each workstream. The workstreams also established advisory development groups to assist in the development and provide wider consultation.

## Methodology

Each workstream used a separate methodology for the development of the guideline.

### Workstream 1

The section on diagnosis and assessment of young children in Part 1 of the guideline is based on the National Autism Plan for Children 2003 (NAPC), which was developed by the United Kingdom National Autistic Society for the National Initiative for Autism: Screening and Assessment in conjunction with the Royal College of Psychiatrists, the Royal College of Paediatrics and Child Health and the All Party Parliamentary Group on Autism<sup>11</sup> The document is available from: [www.nas.org.uk/nas/jsp/polopoly.jsp?d=368&a=2178](http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=368&a=2178). This is the full version on which this part of guideline is based and to which the reader should refer for the evidence base and rationale for recommendations. Further reference was made to the Autistic Spectrum Disorders Best Practice Guidelines for Screening, Diagnosis and Assessment developed by the California Department of Developmental Services 2002,<sup>33</sup> [www.ddhealthinfo.org/asd.asp](http://www.ddhealthinfo.org/asd.asp). Individual members of the Paediatric Society developed appendices 5 and 6 and the evidence-based process that they followed is described there.

The New Zealand Guideline Development Group in Workstream 1 applied the AGREE tool<sup>424</sup> to assess the NAPC Guideline. It was assessed as being an appropriate document to be adapted for the New Zealand environment. Some areas identified by the AGREE assessment required adaptation to reflect the New Zealand context. Adaptation of the NAPC Guideline was undertaken during face-to-face meetings, audio conferencing and email consultation of drafts.

A literature search by NZHTA up until June 2004 was performed to identify evidence on the benefits and harms of pharmacological and biomedical interventions suitable for children with ASD to inform Part 4 of the guideline. The search was aimed at finding literature relevant to children aged 0 to 12 years. A list of abstracts was generated from about 900 papers. A list of relevant papers was generated from these abstracts and evidence tables were compiled. Selection criteria were:

- autism-specific studies – study subjects included individuals diagnosed with ASD
- double-blind randomised controlled trials
- systematic reviews
- case reports of adverse effects (with particular reference to drugs in current use in New Zealand)
- papers of general interest on the topic.

Review of the list of abstracts generated by the NZHTA literature search noted that 70 different medications or biologically active agents have been described as being used therapeutically in ASD and related disorders. In addition, two dietary approaches have been described. Eight classes of medications were reviewed by different authors in Workstream 1 for their applicability to children. Many medications were described in only one or two papers,

often single case reports. A number of the papers reviewed included an age range in the study subjects outside the 0 to 12 years criteria and thus recommendations may have a relevance to older children.

Early in the guideline development process, the Ministry of Health commissioned a New Zealand Health Technology Assessment review, undertaken by Marita Broadstock and Carolyn Doughty, on the evidence relating to the use of psychotropic medication in adults with ASD. However, no adult psychiatrist was identified to evaluate this review and produce recommendations for pharmacotherapy in adults. It is intended that this work be undertaken at a later date.

## Workstream 2

Major sections of Parts 2 and all of Part 3 of the guideline were developed by a small working group consisting of five people with expertise in special education and ASD. Communication was by face-to-face meetings and teleconferences. Additional expertise was incorporated through feedback from a consultancy group. The group developed practice questions which were sent to the consultancy group for feedback and the generation of further questions. The group conducted its own searches of the literature up until April 2004, assisted by the library at the Ministry of Education. Because of time and resource constraints, evidence was drawn primarily from existing published guidelines and published reviews of relevant literature. When insufficient material was found from this method, searches were undertaken for single research studies and other writing from established experts in the field.

The ERIC, PsycINFO and Australian Family Index databases were searched using the descriptors 'autism spectrum disorders', 'autism', 'asperger(s) syndrome', 'pervasive developmental delay' and 'education'. Searches were also undertaken

to seek material on effective practice, adolescents, families, behaviour, transitions and inclusion in relation to ASD. The criteria for selection of studies were as follows:

For guidelines:

- published in 1998 or later
- contained an education focus
- evidence of an evidence-based approach.

For literature reviews and single articles:

- published in a peer reviewed journal in 1998 or later
- had a focus on education and ASD.

Recurring themes were identified. The published evidence was critically appraised and evidence tables developed with levels of evidence for each study. The content of the guideline was decided upon by consensus, based on the sources of evidence. The content was reviewed by the consultancy group for feedback and where that feedback was supported by the evidence, it was added to the document. Consensus was also used to develop recommendations based on the content of the section. Each recommendation was graded according to the strength of evidence that supported it.

### **Workstream 3**

This workstream, set up by the Ministry of Health and the Disability Services Directorate, was made up of two workstream leaders and a virtual team of ASD subject matter experts from across New Zealand. The writers contributed separate sections, reflecting the different expertise of the team members. The workstream leaders were responsible for all of Part 5 of the guideline on the support needs of people with ASD in the community and the transition into adulthood, and half of Part 1, the

assessment and diagnosis of young people and adults. Additional contributions were merged into Parts 2 and 4.

The scope of topics to be included was initially wide ranging but refined after consultation, because of resourcing and time issues. The following topics relevant to young people and adults with ASD were excluded:

- skills for independent living
- socialisation, relationships and sexuality
- behaviour support
- occupational therapy
- physiotherapy
- communication support
- care and protection
- alternative treatments
- interface between relevant New Zealand agencies
- people with ASD over the age of 65 years
- transitions within school, for example, early childhood education to primary school, primary school to secondary school.

Practice questions and topics were defined and a systematic, hierarchical search of medical, psychological and social science databases was performed in July 2004. Further searches were also performed by accessing relevant organisations and internet websites for policy and position papers, textbooks, reports and guidelines. The identified literature was appraised using the New Zealand Guideline Group process. Qualitative research was appraised using the CASP (critical appraisal skill programme) tool. Evidence tables were constructed with levels of evidence for each study. This team consulted an advisory group on a regular basis during the development of the sections.

### **Date range for inclusion of studies**

For all workstreams, systematic searching was performed until 2004. Papers published after the completion of searching and, in some cases before the search dates, were suggested by members of all workstreams and incorporated in the text and evidence tables, where appropriate. In future updates of the guideline, systematic searching will commence in 2004 to ensure a systematic evaluation of all the literature is achieved.

### **Māori and Pacific perspectives**

The process underlying the chapters on Māori and Pacific perspectives is described within these chapters.

### **Consultation**

An open consultation process was undertaken requesting input from stakeholders and other interested individuals and groups, both within New Zealand and overseas. Parallel review of the draft ASD Guideline was also undertaken by a number of experts in ASD nominated by the workstream leaders. Feedback was sought on identification of gaps in the content, links between evidence and recommendations and suggestions on presentation. The workstream leaders considered all the feedback and made amendments supported by additional references, where appropriate.

### **Evidence tables**

The evidence tables that support this guideline can be accessed on the Ministry of Health website (<http://www.health.govt.nz/our-work/disability-services/disability-projects/autism-spectrum-disorder-guideline/supporting-materials-asd-guideline>) No evidence tables were provided for the assessment and diagnosis of children as this section of the guideline

was an adaptation of the NAPC UK Guideline. The evidence tables for the remainder of the guideline are in two separate formats. Evidence tables assessing the benefits and harms of medications follow a strictly quantitative format, based on study design. This format was considered unsuitable to describe the evidence for all other sections of the guideline which include expert opinion and qualitative evidence as well as quantitative studies. All other evidence tables have a broader, more general format to deal with the variety of evidence that has been gathered.

### **Grading**

Each of the recommendations in this guideline is followed by a 'strength of evidence' grading, designated by the letters 'A', 'B', 'C', 'I' or '✓' immediately after the recommendation. These strength of evidence gradings indicate the amount, general quality and clinical applicability (to the guideline topic or question) of scientific evidence used as the basis for each guideline recommendation.

The NZGG grading system was used for developing these 'strength of evidence' grades. Prior to this decision being made, Workstream 1 had used the grades applied by the NAPC UK Guideline. These grades were analysed and converted to NZGG grades, where possible.

The NZGG grading system is a two-tier system with the following steps:

1. Critical appraisal of individual studies  
Each relevant study was critically appraised using a checklist and was assigned an overall level of evidence, indicating whether the study had met most or all of the criteria in the checklist (+), some of the criteria (~) or very few or none of the criteria (-).

## 2. Weighing the body of evidence and development of graded recommendations

For each clinical question, the relevant body of evidence summarised in evidence tables was considered. Decisions were made on the quality (level of evidence), quantity, consistency, applicability and clinical impact of all the studies forming the body of evidence that were relevant to each question. Recommendations were developed based on the evidence by the guideline writers. The recommendations were graded by the following system:

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 Team, this 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 Team or feedback from consultation within New Zealand.	✓

In interpreting the grades attached to each recommendation, it is important to note:

### **The strength of evidence grading does not reflect the importance of the recommendation or its direction.**

For example, it is possible to have A evidence that an intervention works or A evidence that it doesn't work (and that therefore the intervention is not recommended). The grading of 'A' reflects the '**strength of the evidence**' that supports that recommendation. In other cases, it may not be practicable or feasible to perform rigorous scientific studies for some types of interventions or programs. Nevertheless, there may be universal consensus among ASD experts that such an intervention or programme is effective at producing desired outcomes. In this situation, a good practice point would recommend a certain course of action, based on consensus among the workstreams. Thus, the attached grading reflects the rigour of the studies providing the evidence rather than an indication of the importance of the recommendation.

## Appendix 2: ASD Guideline writing teams and management groups

### 1. Writing teams

The members of the Guideline Development Team who had primary responsibility for developing the guideline are as follows:

**Angelika Anderson**

Former Researcher – Research Centre for Interventions in Teaching and Learning

**Kevin Appleton**

Child, Adolescent and Adult Psychiatrist, Auckland

**Giles Bates**

Paediatrician, Midcentral District Health Board, Palmerston North

**Tanya Breen**

**(leader of Workstream 3)**

Consultant Clinical Psychologist, Hamilton

**Veronica Casey**

Former CEO, Paediatric Society of New Zealand, Dunedin

**Matt Eggleston**

Child and Adolescent Psychiatrist  
New Zealand Branch, Faculty Child & Adolescent Psychiatry, Royal Australia and New Zealand College of Psychiatrists  
Representative, Christchurch

**Monique Faleafa**

**(expert in Pacific peoples' issues)**

Clinical psychologist/Pacific advisor, Auckland

**Jill Ford**

Service Manager and occupational therapist, Ministry of Education, Special Education, Blenheim

**Andrea Hasselbusch**

Occupational therapist, Ministry of Education, Auckland

**Lynne Hayes**

Speech-language therapist, Ministry of Education, and Capital and Coast District Health Board, Wellington

**Anne Lethaby**

Technical Editor, Independent evidence-based consultant, Santiago, Chile

**Dannette Marie**

**(expert in Māori issues)**

Adjunct Lecturer, Department of Psychology, University of Otago, Dunedin

**Rosemary Marks**

**(leader of Workstream 1)**

Developmental Paediatrician, Auckland District Health Board, Auckland

**Andrew Marshall**

Developmental Paediatrician, Capital and Coast District Health Board, Wellington

**Keryn Mells**

Primary teacher and parent member of the Autism Spectrum Disorder Intersectoral Advisory Group, Wellington

**Tracey Moore**

Project Manager, ASD Guideline, Ministry of Health, Dunedin

**David Newman**

Developmental Paediatrician, Waikato District Health Board, Hamilton

**Sue Robertson**

**(leader of Workstream 3)**

Project manager for Autism Solutions Ltd and parent for a person with ASD, Auckland

**Adrienne Tomkins**

Speech-language therapist, ex Special School Principal, Verifier, Eligibility Unit  
Ministry of Education, Wellington

**Marilyn Watson**

**(leader of Workstream 2)**

Registered psychologist, Senior Advisor – Autism Spectrum Disorders, Ministry of Education, Special Education, Dunedin



## 2. Consultation advisory groups

### Advisory group for Workstream 1

**Ann Christie**

Senior Occupational Therapist specialising in Child Mental Health, Kari Centre, CAMHS, Auckland District Health Board

**John Clarkson**

Paediatrician, Otago District Health Board, Dunedin

**Tony Hanne**

General Practitioner, Royal College of General Practitioners Representative, Auckland

**Brenda Hynes**

National Clinical Advisor (Nursing), Royal New Zealand Plunket Society (Inc) Plunket National Office, Wellington

**Fran Moore**

Nurse, Spectrum Care, Auckland

**Ulla Preston**

Psychologist, Wellington

**Stephen Voss**

General Practitioner, Invercargill

### Advisory group for Workstream 2

**Jill Bevan-Brown**

Massey University, Palmerston North

**Jen Birch**

Adults with ASD, Auckland

**Marg Crosswell**

Early intervention teacher, Ministry of Education, Special Education, Dunedin

**Marilyn Glover**

Formerly representing New Zealand School Trustees Association, Auckland

**Andrea Hasselbusch**

Occupational therapist, Ministry of Education, Auckland

**Lynne Hayes**

Speech-language therapist, Ministry of Education, Wellington

**Mary Henderson**

Parent/representing families of children/young persons with ASD in Auckland, Auckland

**Chris McGuire**

Parent/Autism New Zealand Inc, Rotorua

**John McKeown**

Principal, Sunnydene Special School, Auckland

**Christine O'Neill**

Tautoko Trust, Nelson

**Cheryl Palmer**

Speech-language therapist, Lead Practitioner ASD, Ministry of Education, Palmerston North

**Maryanne Pease**

Psychologist/Service Manager – Early Intervention, Ministry of Education, Dunedin

**Grant Ramsay**

Early intervention teacher, Ministry of Education, Dunedin

**Mary Smith**

Verifier, Ministry of Education, Auckland

**Clair Wilson**

Special Education Needs Coordinator, Bayfield High School, Dunedin

**Ans Wilkin**

Speech-language therapist, Ministry of Education, Dunedin

**Maree Whitworth**

Parent/Autism New Zealand Inc, Christchurch

**Russell Young**

Principal, Silverdale Normal School, New Zealand Principals' Association, Hamilton

### **Advisory group for Workstream 3**

**Maureen Arathoon**

Lecturer and Clinical Psychologist, Massey University and Ministry of Education, Levin

**Jen Birch**

Adults with ASD, Auckland

**Anne Bray**

Clinical psychologist, Donald Beasley Institute, Dunedin

**Stephanie Charteris**

Occupational therapist and therapy team leader, Oaklynn Special School, Auckland

**Mary Foster**

Associate Professor in Psychology, University of Waikato, Hamilton

**Dee Gulliver**

Access Ability, Auckland

**Nan and Soren Jensen**

Parents of a person with ASD, Te Kowhai

**LeAnne Kingi**

Māori advisor, LIFE Unlimited, Hamilton

**Dave Lennard**

Adults with ASD, Auckland

**Steven Lillas**

General practitioner and trainer of GPs, Hamilton

**Chris McGuire**

Parent/Autism New Zealand Inc, Rotorua

**Amica Petrova**

Psychiatrist, Child and Adolescent Mental Health, Hamilton

**Angela Preston**

NASC representative, Service Facilitator for Children and their Families, Access Ability Dunedin

**Alison Schroeder**

Speech-language therapist, Christchurch

**Raewyn and Martin Upsdell**

GP and scientist (respectively) and parents of a person with ASD, Hamilton

**Robyn Ward**

Parent of a person with ASD, Hamilton

**Jan White**

Disability Support Link, Hamilton

**Maree Whitworth**

Parent/Autism New Zealand Inc, Christchurch

**Anne Wilkinson**

National Services Coordinator, Parent to Parent, and parent of a person with ASD, Hamilton

### **Advisory group for Māori perspectives**

**Mere Berryman**

Manager, Poutama Pounamu Educational Research Centre, Ministry of Education, Tauranga

**Leo Buchanan**

Te Āti Awa and Taranaki Iwi, Paediatrician, Hutt Hospital, Lower Hutt

**Papara Carroll**

Former Project Manager, Māori Development, Disability Services Directorate, Ministry of Health, Wellington

**Roger Jolley**

Manager, Māori Development, Disability Services Directorate, Ministry of Health, Wellington

**Aroha Morgan**

Māori Development Manager, Tainui MAPO, Auckland

### **Advisory group for Pacific perspectives**

**Manase Lua**

Project Manager Pacific, Disability Services Directorate, Ministry of Health, Auckland

### 3. Steering Group

#### **Basia Arnold**

Principal Technical Specialist, Mental Health Directorate, Ministry of Health, Wellington

#### **Jen Birch**

Adults with ASD, Auckland

#### **Karin Bowen**

Former Project Manager, Ministry of Health, Dunedin

#### **Tanya Breen**

Workstream Leader, Support and Transition Workstream, Hamilton

#### **Joanna Curzon**

Team Leader – Research, Professional Practice, Ministry of Education, Wellington

#### **Jan Dowland**

Manager Specialist Services, IDEA Services, Wellington

#### **Wendy Duff**

President, Autism New Zealand Inc, Auckland

#### **Monique Faleafa**

Pacific Advisor, Auckland

#### **Denise Guy**

Psychiatrist, Faculty of Child and Adolescent Psychiatrists, New Zealand Branch, Lower Hutt

#### **Dave Lennard**

Adults with ASD, Auckland

#### **Chris McGuire**

Former President, Autism New Zealand Inc, Rotorua

#### **Rosemary Marks**

Workstream Leader, Assessment and Diagnosis Workstream, Auckland

#### **Nic McKenzie**

Team Leader ASD, IDEA Services, Christchurch

#### **John McKeown**

New Zealand Special Schools, Auckland

#### **Tracey Moore**

Project Manager, Ministry of Health, Dunedin

#### **Gill Mudford**

Behaviour Therapist, Spectrum Care, Auckland

#### **Gina Paerata**

Former Analyst, Māori Health Directorate, Ministry of Health, Wellington

#### **Sue Robertson**

Workstream Leader, Support and Transition Workstream, Auckland

#### **David Russell-Jones**

Executive Manager, Operations Governance, Child, Youth and Family, Wellington

#### **Karen Scott**

Development Manager, Children & Families, Ministry of Health, Wellington

#### **Elaine Spark**

Service Manager, Ohomairangi Trust, Early Intervention Services, Auckland

#### **Simone Stanfield**

Team Leader, Spectrum Care, Auckland

#### **Mereti Taipana**

Former Supportlinks/ENABLE, Needs Assessment & Service Coordination Services, Palmerston North

#### **Pat Tuohy**

Chief Advisor – Child & Youth Health, Ministry of Health, Wellington

#### **Marilyn Watson**

Workstream Leader, Education Workstream, Dunedin

#### **Rod Watts**

Former Planning and Development Manager, Disability Services Directorate, Ministry of Health, Auckland

#### **Maree Whitworth**

Former CEO, Autism New Zealand Inc, Christchurch

#### 4. Senior Officials Group/ASIWG

**Basia Arnold**

Principal Technical Specialist, Mental Health Directorate, Ministry of Health, Wellington

**Annie August**

Regional Project Advisor, Ministry of Social Development, Wellington

**Hannah Cameron**

Senior Policy Analyst, Education Management Policy, Ministry of Education, Wellington

**Karen Coutts**

Former Senior Analyst, Mental Health Policy and Service Development, Mental Health Directorate, Ministry of Health, Wellington

**Joanna Curzon**

Team Leader – Research, Autism Spectrum Disorder (ASD) National Team, Special Education, Ministry of Education

**Elaine Joyce**

Former Policy Advisor, Child, Youth and Family, Wellington

**Karl Le Quesne**

Senior Manager, Education Management Policy, Ministry of Education, Wellington

**Lynda Little**

Senior Advisor, Child, Youth and Family, Wellington

**Karen McConnochie**

Former Development Manager, Children & Families, Ministry of Health, Wellington

**Lester Mundell**

Chief Advisor, Disability Services Directorate, Ministry of Health, Wellington

**Gina Paerata**

Former Analyst, Māori Health Directorate, Ministry of Health, Wellington

**David Russell-Jones**

Executive Manager, Operations Governance, Child, Youth and Family, Wellington

**Karen Hunter**

Development Manager, Children & Families, Ministry of Health, Wellington

**Carol Searle**

Former Deputy Director General, Disability Services Directorate, Ministry of Health, Wellington

**Pat Tuohy**

Chief Advisor – Child & Youth Health, Ministry of Health, Wellington

**Rod Watts**

Former Planning and Development Manager, Disability Services Directorate, Ministry of Health, Auckland

#### 5. Living Guideline Group membership (in alphabetical order)

**Jill Bevan-Brown (LGG Member)**

Director (retired), Inclusive Education Research Centre, Institute of Education, Massey University

**Tanya Breen (LGG Member)**

Consultant Clinical Psychologist, Specialist in Autism Spectrum Disorder and Disability Issues

**Marita Broadstock (LGG Project Manager, lead researcher, and technical editor for second edition of the NZ ASD Guideline)**

Director, INSIGHT Research Ltd

**Sally Clendon (LGG Member)**

Senior Lecturer, Speech and Language Therapy Programme, Institute of Education, Massey University

**Joanna Curzon (past LGG ex-officio)**

Team Leader – Research, Autism Spectrum Disorder (ASD) National Team, Special Education, Ministry of Education

*We report with great sadness that Joanna passed away in 2013.*

**Elizabeth Doell (past LGG member, past LGG ex-officio)**

Senior Lecturer, Specialist Teaching Programme Coordinator, University of Canterbury

**Matt Eggleston (LGG Chair)**

Child and Adolescent Psychiatrist, Clinical Head, Child and Family Specialty Service, Canterbury DHB

**Ian Evans (past LGG Chair)**

Emeritus Professor of Psychology, Massey University

**Debbie Fewtrell (LGG Member)**

General Practitioner (special interest in autism spectrum disorder), Kerikeri

**Matt Frost (LGG Member, and past LGG Chair)**

Senior Advisor, Office for Disability Issues, Ministry of Social Development

**Natasha Gartner (LGG ex-officio)**

ASD Project Manager, Family and Community, Disability Support Services,

National Services Purchasing, National Health Board, Ministry of Health

**Pamela Henry (past LGG ex-officio)**

Development Manager, Family and Community Support Team, Disability Support Services, Health & Disability National Services Directorate, Ministry of Health

**Julie Hook (LGG ex-officio)**

National Manager, Practice, Special Education, Sector Enablement and Support, Ministry of Education

**Andrew Marshall (LGG Deputy Chair)**

Developmental Paediatrician, Child Development Team at Puketiro Centre, Porirua and Clinical Leader, Child Health, Wellington Hospital

**Leigh Sturgiss (past LGG ex-officio)**

ASD Project Manager, Family and Community, Disability Support Services, National Services Purchasing, National Health Board, Ministry of Health

## Appendix 3: List of submitters to the draft ASD Guideline

### 1. Open consultation

The following individuals or groups who provided feedback on the draft ASD Guideline agreed to the publication of their names.

Name	Position	Additional people contributing	Organisation (blank if individual)
Adams, Alison and Laurie	Parents of 2 autistic children	1	
Allan, Judi	Developmental teacher	6	Sommerville Special School
Anderson, Maureen	Manager	5	Child Development Centre, Waikato Hospital
Anonymous	Consultant and parents		Acorn House
Bawden, Jane	Committee member	–	Autism Association NZ (Auckland branch)
Bendikson, Kathy	Unknown		
Benge, Trisha	Centre director	5	McKenzie Centre
Bialostocki, Catherine	General practitioner and parent of a child with ASD	1	
Birnie, Ros	Principal	3	Waitaha Learning Centre
Blampied, Neville	Associate Professor and Head of Department	–	Department of Psychology, University of Canterbury
Blount, Wendy	Secretary / Treasurer	6	Taranaki APEPSI Trust
Byrne, Helen; Walker, Janet; Shanks, Atholea	Occupational therapist; special education advisers	–	Ministry of Education, Special Education
Challies, Danna	Post doctoral behaviour researcher / parent of a child with ASD and parented by parent with AS	–	
Clark, Marion	Chief Executive	–	Nursing Council of NZ
Clark, Phillipa	Senior Lecturer	–	Department of Paediatrics, University of Auckland
Coombes, Kara	Service Leader (Senior Clinical Social Worker / Family Therapist)	1	Child, Adolescent and Family Mental Health, Alcohol and Other Drug Service
Cox, Andrew	Psychiatrist	6	Kari Centre, Auckland District Health Board
Davis, Lyn	Team Leader, Child Development and VNT/OT	2	Tairāwhiti District Health Board
Doak, Verity	National Director	–	The Personal Advocacy Trust Inc
Downs, Sharon	Coordinator	3	Cloud 9 Children's Foundation
Eggleston, Matt	Psychiatrist	–	Canterbury District Health Board
Ellender, Michelle	Unknown	1	

<b>Name</b>	<b>Position</b>	<b>Additional people contributing</b>	<b>Organisation (blank if individual)</b>
Farrelly, Maree	Parent of 2 children with ASD and one child without ASD	–	
Fauchelle, Doug	Advisor, Service Development Group	2	Child, Youth and Family
Foster-Cohen, Susan	Director	2	The Champion Centre
Frankish, Fay	Retired	–	
Frost, Matt	Policy and Information Researcher	–	CCS Disability Action National Office
Gray, Rodney and Betsy	Parents of an adult with ASD	–	
Green, Gina	Lecturer / consultant	–	San Diego State University and private practice, USA
Groos, Catherine	Special education teacher	–	NZ primary school
Hainsworth, Rebecca; Rei, Josie	Occupational therapist, social worker, Strengthening Families public health nurse	–	Community Health Services, Waikato Health
Hayes, Lynne	Speech-language therapist	6	Ministry of Education, Special Education, Porirua Office
Hayward, Margaret Rose	Caregiver, grandparent	–	
Howard, Kerry; Speri, Barbara	Special education teachers	–	Central Normal School, Freyberg High School
Huttley, Bev	Clinical Team Leader	6	CAMHS
Jackson, Karen	Manager	3	Southern Behaviour Support
Jones, David	Community and general paediatrician	–	Bay of Plenty District Health Board
Keenan, Mickey	Senior Lecturer	–	School of Psychology, University of Ulster, Northern Ireland
King, Linda	Acting Deputy Principal	1	Allenvale School (special needs school)
Laidlaw, Robyn	Deputy Principal	12	Ruru School, Waikiwi (special needs school)
Legg, Sally	Arts therapist clinical intern	–	Spark Studio (visual arts and creative development programme for people with disabilities)
Liberty, Kathleen	Coordinator, Early Intervention Programme	–	School of Education Studies and Human Development and Health Sciences Centre
Litteck, Celeste	Consultant and advisor on ASD	–	Logical Developments Ltd and Fairhaven School
Macmillan, Lorraine	Unknown	–	
Martin, Jill; McKellar, Denise	Training Managers	2	Autlink Foundation Inc
Masson, Leila	Paediatrician	>30	Group of doctors and other health professionals
McDowell, Rochelle	Parent of a child with ASD	–	

<b>Name</b>	<b>Position</b>	<b>Additional people contributing</b>	<b>Organisation (blank if individual)</b>
McGuigan, Heather	Wife, daughter, mother, sister and aunty of persons with ASD	–	
McGuire, Chris	Parent of a child with ASD	–	
McKenzie, Nic	National Service Leader, ASD	>20	Idea Services, IHC NZ
McLean, Judi	Early intervention teacher	–	Ohomairangi Trust Early Intervention Service
McMenamin, Trish	Lecturer	–	School of Education Studies and Human Development, University of Canterbury
Messick, Erik	Lecturer	10	Psychology Department, University of Waikato
Miers, Vicky	Regional Service Manager	5	Community Living Trust
Miller, Bonnie	Clinical psychologist	3	Mental Health and Addiction Services, Dual Disability Service
Miller, Caroline	Co-director, Master of Arts in Arts Therapy programme	–	Whitecliffe College
Morton-Macphail, Keith	Committee member	6	Autistic Spectrum Disorder Information Network
Moss, Jan	Coordinator	10	Complex Carers Group
Mudford, Oliver; Arnold-Saritepe, Angela; Rose, Dennis	Psychologists	–	Staff of the Applied Behaviour Analysis postgraduate programme, University of Auckland
Nel, Judith	Principal	4	Parkside School (special needs school)
Newman, Valerie	Parent	–	
New Zealand Association for Behaviour Analysis	Group members	100	New Zealand Association for Behaviour Analysis
Nolan, Chris	General Manager, Mental Health	4	Southland District Health Board
Parsons, Cathie	Parent of 3 ASD children	–	
Payton, Adrienne	Parent of a child with ASD	1	
Petorius, Andri	Occupational therapist	–	Child and Family Specialty Service, Canterbury District Health Board
Phillips, Katrina; Ford, Erika; Jeffery, Kylie; Loche, Janine; Taylor, Sarah	Intern and graduate students	–	ABA programme at University of Auckland
Porteous, Louise	Consultant paediatrician	2	Kidzfirst
Ratnam, Carol	Analyst	–	Office for Disability Issues
Richardson, Jacki	CEO	10	Spectrum Care Trust Board
Rickson, Daphne	Music therapy lecturer	25	NZ Society for Music Therapy
Robertson, Neil	Parent of person with ASD	–	



<b>Name</b>	<b>Position</b>	<b>Additional people contributing</b>	<b>Organisation (blank if individual)</b>
Ross, D. Malcolm	Past teacher, principal and grandmother of child with ASD	1	
Ross, Sandy	Member, Health and Disability Portfolio	–	NZ Association of Counsellors
Sands, Madeleine	Team Leader	–	Child Development Team, Auckland District Health Board
Schofield, Soe	Special education facilitator	–	Ministry of Education
Scott, Gabrielle	Coordinator, Child Development Service	4	Midcentral Health
Smith, Tristram	Associate professor of paediatrics	–	Strong Centre for Developmental Disabilities, University of Rochester Medical Centre, USA
Stace, Hilary	Parent of child with ASD	–	
Stanbridge, Chris	Unknown	1	
Stephenson, Eddie	Registered psychologist	–	Explore Specialist Services
Stewart, Pauline	Lead practitioner and educational psychologist	–	Ministry of Education
Stone, Harold	President of support network and person with AS	–	Asperger's Syndrome Support Network/ Asperger Services, Australia
Swan, Catherine	Developmental paediatrician	8	Department of Paediatrics, Canterbury District Health Board
Taipana, Mereti	Parent and professional	–	Private practice (social services)
Taute, Liz	Director of learning, Motuora Special Needs Unit	3	Red Beach Primary School (special needs unit)
Tawroszewicz, Maryska	Senior clinical psychologist and ASD team coordinator	4	Child and Family Specialty Service
Taylor, Jill; Kane, Paul	Parents of a child with ASD	1	
Thomas, Sue	Early intervention teacher	–	Ministry of Education, Special Education
Trounson, Mary	Parent of a child with AS	–	
Trounson, Stuart	Parent	–	
Tsang, Bobby	Paediatrician	4	Waitemata District Health Board
Turnbull, Sarah; Kelly, Wendy; Cohen, Pamela; Appleby, Kris; Osmond, Mike		–	Autism Intervention Trust
Vincent, Prue	Special education facilitator	–	Ministry of Education
Ward, Stella	President	1	NZ Speech-Language Therapist Association
Watkins, Dr W.G.A.	Clinical head and child and adolescent psychiatrist	–	Child, Adolescent and Family Mental Health Service
Weiss, Mary Jane	Associate professor and director of research and training	–	Rutgers University, USA

<b>Name</b>	<b>Position</b>	<b>Additional people contributing</b>	<b>Organisation (blank if individual)</b>
Whitley, Barbara	Manager of School, Immersion and Residential	–	Homai Campus School, Blind and Low Vision Education Network, NZ
Whitworth, Maree	CEO	45	Autism New Zealand Inc

## 2. Expert peer review

The following expert peer reviewers were nominated by the Workstream Leaders and they provided feedback on the draft ASD Guideline.

<b>Name</b>	<b>Position</b>	<b>Parts reviewed</b>
Attwood, Tony	Professor, Asperger's Syndrome Clinic, Queensland, Australia	All
Belton, Richard	Parent/Board Member of Autism New Zealand	All
Collins, Michael	Head of Education Services, National Autistic Society, United Kingdom	All
Filipek, Pauline	Associate Professor of Pediatrics and Neurology, University of California, Irvine, USA	All
Jordan, Rita	Professor, Autism Centre for Education and Research, University of Birmingham, United Kingdom	All
Le Couteur, Ann	Professor of Child and Adolescent Psychiatry, Child and Adolescent Mental Health, University of Newcastle, United Kingdom	All
Moore, Dennis	Professor, Faculty of Education, Monash University, Australia	2, 3
Morgan, Hugh	Chief Executive, Autism Cymru, Wales	2, 5 and section in Part 1 which concerned young people/adults
Werry, John	Child and Adolescent Psychiatrist, Auckland, New Zealand	All

## Appendix 4: Diagnostic criteria for ASD (DSM-IV-TR, ICD-10, and DSM-5)

### 1. DSM-IV-TR

**Note:** DSM-IV-TR criteria were revised in the latest version of the Diagnostic and Statistical Manual for Mental Disorders, the DSM-5.<sup>19</sup> The implications of the DSM-5 for the guideline were considered by the Living Guideline Group in their Supplementary Paper,<sup>16</sup> which is summarised in Appendix 10.5. A summary of differences between DSM-IV-TR and DSM-5 are presented in section 3 of this Appendix.

#### 299.00 Autistic Disorder

#### A. A total of six (or more) items from (1), (2) and (3), with at least two from (1), and one each from (2) and (3):

- (1) qualitative impairment in social interaction, as manifested by at least two of the following:
  - (a) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
  - (b) failure to develop peer relationships appropriate to developmental level
  - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (eg, by a lack of showing, bringing, or pointing out objects of interest)
  - (d) lack of social or emotional reciprocity
- (2) qualitative impairments in communication as manifested by at least one of the following:

- (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)
  - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
  - (c) stereotyped and repetitive use of language or idiosyncratic language
  - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- (3) restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:
    - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
    - (b) apparently inflexible adherence to specific, non-functional routines or rituals
    - (c) stereotyped and repetitive motor mannerisms (eg, hand or finger flapping or twisting, or complex whole body movements)
    - (d) persistent preoccupation with parts of objects

#### B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication or (3) symbolic or imaginative play

- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder**

#### 299.80 Asperger's Disorder

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:**

- (1) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
- (2) failure to develop peer relationships appropriate to developmental level
- (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (eg, by a lack of showing, bringing or pointing out objects of interest to other people)
- (4) lack of social or emotional reciprocity

- B. Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:**

- (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (2) apparently inflexible adherence to specific, non functional routines or rituals
- (3) stereotyped and repetitive motor mannerisms (eg, hand or finger flapping or twisting, or complex whole-body movements)
- (4) persistent preoccupation with parts of objects

- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.**

- D. There is no clinically significant general delay in language (eg, single words used by age 2 years, communicative phrases used by age 3 years).**

- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.**

- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.**

#### 299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behaviour, interest, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes 'atypical autism' – presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

*The diagnostic criteria for DSM-IV-TR have been reprinted with permission from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision, (Copyright 2000). American Psychiatric Association.*

## 2. ICD-10

### F84 Pervasive developmental disorders

A group of disorders characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual's functioning in all situations.

Use additional code, if desired, to identify any associated medical condition and mental retardation.

#### F84.0 Childhood autism

A type of pervasive developmental disorder that is defined by: (a) the presence of abnormal or impaired development that is manifest before the age of three years, and (b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour. In addition to these specific diagnostic features, a range of other nonspecific problems are common, such as phobias, sleeping and eating disturbances, temper tantrums, and (self-directed) aggression.

Autistic disorder Infantile:

- autism
- psychosis

Kanner's syndrome

Excludes: autistic psychopathy (F84.5)

#### F84.1 Atypical autism

A type of pervasive developmental disorder that differs from childhood autism either in age of onset or in failing to fulfil all three sets of diagnostic criteria. This subcategory should be used when there is abnormal and

impaired development that is present only after age three years, and a lack of sufficient demonstrable abnormalities in one or two of the three areas of psychopathology required for the diagnosis of autism (namely, reciprocal social interactions, communication, and restricted, stereotyped, repetitive behaviour) in spite of characteristic abnormalities in the other area(s). Atypical autism arises most often in profoundly retarded individuals and in individuals with a severe specific developmental disorder of receptive language.

Atypical childhood psychosis

Mental retardation with autistic features

Use additional code (F70-F79), if desired, to identify mental retardation.

#### F84.5 Asperger's syndrome

A disorder of uncertain nosological validity, characterized by the same type of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. It differs from autism primarily in the fact that there is no general delay or retardation in language or in cognitive development. This disorder is often associated with marked clumsiness. There is a strong tendency for the abnormalities to persist into adolescence and adult life. Psychotic episodes occasionally occur in early adult life.

Autistic psychopathy

Schizoid disorder of childhood

#### F84.8 Other pervasive developmental disorders

#### F84.9 Pervasive developmental disorder, unspecified

*The diagnostic criteria for ICD-10 have been reprinted with permission from the World Health Organization.*

### 3. DSM-5

The following table summarises the differences between DSM-IV-TR and DSM-5 Criteria for ASD.

Summary of differences between DSM-IV-TR and DSM-5 Criteria adapted from Halfon & Kuo (2003).<sup>434</sup>

DSM-IV-R: Autistic Disorder	DSM-5: Autism Spectrum Disorder
Number of criteria=12, minimum criteria=3, domains=3	Number of criteria=7, minimum criteria=5, domains=3
<b>Social Interaction Domain</b> (minimum required: ≥2 of 4)	<b>Social Interaction and Social Communication</b> (minimum required: all 3)
<b>1A.</b> Marked impairments in the use of multiple nonverbal behaviors to regulate social interaction	<b>A2.</b> Deficits in nonverbal communicative behaviors used for social interaction
<b>1B.</b> Failure to develop peer relationships appropriate to developmental level	<b>A3.</b> Deficits in developing and maintaining relationships appropriate to developmental level
<b>1C.</b> A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people	(Subsumed into <b>A1</b> )
<b>1D.</b> Lack of social or emotional reciprocity	<b>A1.</b> Deficits in social emotional reciprocity
<b>Communication Domain</b> (minimum required: ≥2 of 4)	<b>Social Interaction and Social Communication</b> (minimum required: all 3)
<b>2A.</b> Delay in, or total lack of, the ability to use spoken language	(Criterion removed)
<b>2B.</b> Marked impairment in the ability to initiate or sustain a conversation with others	(Subsumed into <b>A1</b> )
<b>2C.</b> Stereotyped or repetitive use of language or idiosyncratic language	(Subsumed into <b>B1</b> )
<b>2D.</b> Lack of varied, spontaneous make-believe or social imitative play appropriate to developmental level	(Subsumed into <b>A3</b> )

DSM-IV-R: Autistic Disorder	DSM-5: Autism Spectrum Disorder
Restricted Interests and Repetitive Behaviors Domain (minimum: ≥1 of 4)	Restricted Interests and Repetitive Behaviors Domain (minimum required: ≥2 of 4)
<b>3A.</b> Encompassing preoccupation with ≥1 stereotyped and restricted pattern of interest abnormal in intensity or focus	<b>B3.</b> Highly restricted fixated interests that are abnormal in intensity or focus
<b>3B.</b> Apparently inflexible adherence to specific routines or rituals	<b>B2.</b> Excessive adherence to routines, ritualised patterns of verbal or nonverbal behavior, or excessive resistance to change
<b>3C.</b> Stereotyped and repetitive motor mannerisms	<b>B1.</b> Stereotyped or repetitive speech, motor movements, or use of objects
<b>3D.</b> A persistent preoccupation with parts of objects	<i>(Criterion removed or possibly subsumed into B3)</i>
	<b>B4.</b> Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment
	<b>Additional criteria for DSM-5: Autism spectrum disorder</b>
	<b>C.</b> Symptoms must be present in early childhood (but may not fully manifest until social demands exceed limited capacities)
	<b>D.</b> Symptoms together limit and impair everyday functioning
	<b>E.</b> Intellectual disability or global developmental delay should be considered as preferential diagnoses

## Appendix 5: The role of diagnostic tools in diagnosing ASD

Autism is a behaviourally defined disorder for which no biological markers currently exist. In addition, there is controversy about diagnostic entities within the autism spectrum disorder continuum such as Asperger syndrome/disorder and pervasive developmental disorder (PDD). Screening and diagnosis therefore depend upon behavioural observation within conceptual frameworks that are reflected in the structure of different tools. It is evident that appropriately developed tools guide observation and history taking, allowing earlier, more reliable and repeatable assessment.

A range of tools with different characteristics exist for both screening/surveillance and diagnosis. The development of new tools is ongoing. Therefore, it is recommended that tool selection be reviewed on an ongoing basis to allow new tools with appropriate sensitivity and specificity to be incorporated into future iterations of the New Zealand ASD Guideline.

### Process

A literature review was undertaken to address the role of diagnostic tools in diagnosing ASD. This topic was broken down into specific questions on each identified tool as follows:

1. What evidence is there that the tool is a valid instrument for the diagnosis of ASD?
2. What population has the tool been validated on?
3. Is the tool applicable to a New Zealand setting? Can the tool be used without modification with Māori, Pacific and Asian individuals?
4. How long does it take to administer the tool?
5. How many professionals are needed to administer the tool?
6. What is needed to make the tool available in New Zealand? Training? Qualifications required? Where can training be accessed? What is the cost of training? Ongoing costs – royalties?
7. What evidence is there that the tool leads to earlier or more accurate diagnosis?
8. How does the cost of using the tool compare with other methods including experienced clinician assessment?

A bibliography was prepared by NZHTA in April 2004 at the request of Lester Mundell, Chief Advisor, Disability Support Services, Ministry of Health. The search strategy is outlined in the report that was submitted to the Ministry of Health. In summary, a comprehensive number of online bibliographic databases, review- and evidence-based databases, library catalogues and international government health websites were searched using a variety of search terms, together with related words, around the themes of ‘differential diagnosis’, ‘questionnaires’, ‘sensitivity and specificity’ and ‘autism’.

Abstracts and/or titles (where the abstract was not available) from the resulting 327 items were scanned for relevance. Articles were selected on the basis of relevance to answering the



above questions. Articles relating to adults, pilot studies, short reports or tools that were not developed or available in English were eliminated from consideration.

During the process of selection of evidence, an important review was identified, that had analysed systematically all relevant evidence (2750 articles) published up to 1998.<sup>44</sup> This report was the work of a multidisciplinary Consensus Panel initiated by the Child Neurology Society and the American Academy of Neurology and later expanded to include representatives of nine professional organisations, four parent organisations with liaison from the US National Institutes of Health. It was decided to accept this review as a definitive summary of all evidence before 1998. Twenty-one additional relevant studies were identified from the search from 1998 onwards.

The following recommendations were developed from individual questions.

**1. What evidence is there that the tool is a valid instrument for the diagnosis of ASD?**

Conclusions:	Grade
<p>Sensitive and specific developmental screening instruments include:</p> <ul style="list-style-type: none"> <li>• Ages and Stages Questionnaire (ASQ)</li> <li>• BRIGANCE Screens</li> <li>• Child Development Inventories (CDI)</li> <li>• Parents' Evaluations of Developmental Status (PEDS).</li> </ul>	A
<p>Autism-specific screening tools that have adequate sensitivity and specificity include:</p> <ul style="list-style-type: none"> <li>• Checklist for Autism in Toddlers (CHAT)</li> <li>• Autism Screening Questionnaire (ASQ).</li> </ul>	B
<p>Diagnostic tools for autism that have been shown to have adequate sensitivity and specificity include the following:</p> <ul style="list-style-type: none"> <li>• Gilliam Autism Rating Scale (GARS). This is a checklist, DSM-IV based, with an age range of 3–22 years, giving a global rating of autism symptomatology.</li> <li>• Parent Interview for Autism (PIA). This is a structured interview with 118 items that takes 45 minutes to deliver.</li> <li>• Autism Diagnostic Interview – Revised (ADI-R). This is currently one of the two best available reference points for diagnosis of ASD. It is a comprehensive structured parent interview which takes one hour to deliver, with specific training and validation procedures.</li> <li>• Childhood Autism Rating Scale (CARS). This is a structured interview and observations with 15 items, designed for children &gt; 24 months, which takes 30–45 minutes to deliver.</li> <li>• Autism Diagnostic Observation Schedule – Generic (ADOS-G). This is currently one of the two best available reference points for diagnosis. It is a semi-structured observational assessment in four modules. It gives DSM-IV and ICD-10 diagnoses with definitive cutoff scores and takes 30 to 45 minutes to deliver.</li> </ul>	B
The Denver II tool cannot be recommended.	B

There are several other tools under development, some of which are mentioned in the American Practice Parameter<sup>45</sup> but which have not yet achieved wide acceptance.

**Note:** Screening instruments are generally less expensive, less time consuming and require less training than diagnostic tools.

- 2. What population has the tool been validated on?**
- 3. Is the tool applicable to a New Zealand setting? Can the tool be used without modification with Māori, Pacific and Asian individuals?**
- 4. How long does it take to administer the tool?**
- 5. How many professionals are needed to administer the tool?**
- 6. What is needed to make the tool available in New Zealand? Training? Qualifications required? Where can training be accessed? What is the cost of training? Ongoing costs – royalties?**

No autism-specific screening or diagnostic tool has been validated in either the New Zealand or Australian settings. Although some tools reported in the English language literature have been adapted and utilised in Chinese and in Japanese populations, no reports exist of studies in Māori or Pacific populations. This represents a clear opportunity for New Zealand to do this work as a part of the internal audit of the guideline.

- 7. What evidence is there that the tool leads to earlier or more accurate diagnosis?**

Recommendations:	Grade
Experienced clinicians are usually necessary for accurate and appropriate diagnosis of autism. Clinical judgment may be aided by diagnostic guides such as DSM-IV or ICD-10 as well as assessment tools, checklists and rating scales.	B
Comprehensive multidisciplinary assessment is recommended as being most important for autism diagnosis compared with other developmental disabilities.	B

- 8. How does the cost of using the tool compare with other methods including experienced clinician assessment?**

Cost analysis was not a part of the search strategy for this literature review so no formal answer is possible. However, it is unlikely that there are any cost analyses comparing diagnostic tools with clinician assessment in the literature. Different tools have been compared with each other yielding kappa scores for agreement from as low as 0.23 to as high as 0.8.

## Appendix 6: The role of cognitive assessment in diagnosing ASD

### Process

A literature review was undertaken to address the role of cognitive assessment in diagnosing ASD. This topic was broken down into specific questions as follows:

1. Does performing a baseline cognitive assessment in individuals with ASD improve outcome?
2. Does performing a baseline cognitive assessment in individuals diagnosed with ASD enable more effective planning of an intervention programme and more efficient use of resources?

A bibliography was prepared by The Clearing House for Health Outcomes and Health Technology Assessment in March 2004 at the direction of Lester Mundell, Chief Advisor, Disability Support Services, Ministry of Health. The search strategy is outlined in the report submitted to the Ministry of Health. In summary, a comprehensive number of online bibliographic databases, review- and evidence-based databases, library catalogues and international government health websites were searched using a variety of search terms (together with related words) around the themes of 'cognitive', 'diagnosis' and 'autism'.

Abstracts and/or titles (where abstracts were not available) from the identified studies (n = 183) were analysed and given a preliminary grading on the basis of the likely degree of relevance in terms of capacity to answer the above questions. The selected articles are included in evidence tables with the following relevance grading:

- Highly relevant (n=18)
- Probably relevant (n=36)
- Possibly relevant (n=23)
- Not relevant (n=106)

The 77 articles selected as being relevant were obtained through online and available library sources. Not all were able to be obtained for the first analysis. Of the above articles or publications, 15 of the Highly Relevant (83%), 19 of the Probably Relevant (53%) and 11 of the Possibly Relevant (52%) were obtained. The list and abstracts of those not obtained were peer-reviewed by a subgroup of the Guideline Development Team, and a decision was made to seek a further four articles. Eighty-one were finally subjected to analysis.

The analysed articles had a number of different study designs: reviews, guidelines, cohort studies (of groups of "higher functioning" autistic children who had cognitive tests at baseline and at follow-up) and studies of cognitive differences and styles in autism versus controls (either normal peers or those with intellectual or language difficulties). Relevant cohort and case control studies were reviewed using an evidence template.

Conclusions	Grade
There are particular patterns of skills and weaknesses on formal tests of cognition associated with autism (but none are so specific that they significantly contribute to the clinical diagnosis).	A
Specific underlying cognitive deficits are postulated to be at the core of the symptoms observed (theory of mind deficit, executive function deficit, weak central coherence).	C
Achievement level in formal tests of non-verbal cognition (ie, IQ score) and language are consistently identified as the best predictors of outcome/prognosis.	A

Recommendation:	Grade
Formal baseline cognitive and/or developmental assessment is recommended at diagnosis.	B

Answers to the research questions can be summarised as follows:

**1. Does performing a baseline cognitive assessment in individuals with ASD improve outcome?**

There is no evidence for or against this, but there is good evidence it allows better prediction of prognosis.

**2. Does performing a baseline cognitive assessment in individuals diagnosed with ASD enable more effective planning of an intervention programme and more efficient use of resources?**

There is no evidence for or against this, but extrapolation from studies supports the conclusion that better definition of learning skills and prognosis by cognitive assessment will assist planning optimal intervention.

Expert supporting opinion from the studies can be summarised as follows:

- (a) Cognition is not part of the clinical criteria for autism but it is an important variable that influences diagnosis, is related to associated medical disabilities (such as epilepsy), and predicts outcome. Measures of nonverbal problem solving in “high functioning” individuals with autism correlate with outcome (whereas) the severity of autistic behaviours is a poor predictor of prognosis.<sup>434</sup>
- (b) It is now recognised that assessment of cognitive functioning is crucial to the differentiation of ASD from other disabilities and to the identification of concomitant impairment in a child with an ASD. Cognitive ability also has an important role in prognosis and intervention planning. An estimation of potential is necessary for the following reasons:

- Functioning level, which includes cognitive and adaptive evaluation, is important for differential diagnosis and intervention planning. A diagnosis of ASD is appropriate when a child shows communicative, social or interest deficits that are inconsistent with overall cognitive functioning. For example, a child of 4 who is functioning at a 12-month developmental level would not receive a diagnosis of ASD if he or she displayed communicative and play behaviours similar to that of other 12-month-old children. It is also extremely difficult to document significant social and communicative deficits below this age level.
- Treatment research generally has supported the notion that response to various treatment approaches has some relation to overall cognitive functioning.<sup>436</sup> For example, certain intensive behavioural approaches have been shown to be less successful with children at lower cognitive levels who are unlikely to develop spoken language.
- Degree of cognitive functioning may indicate expected rates of progress. This, of course, is dependent upon the relative degree of certainty with which cognitive impairment can be established.<sup>41</sup>

## Appendix 7: Core elements of effective teaching of individuals with ASD

In Appendix 7, the core elements of effective teaching described in 3.4 Education sector organisation and management are expanded and tables show possible barriers and ways to implement these elements in the New Zealand context. Considerations and barriers at two age levels (roughly equating to primary and secondary) are summarised in the accompanying text boxes. This material has been drawn from the work of Marks et al. and from the practice experience and knowledge of the Guideline Development Team from the education workstream.<sup>229</sup>

### 1. Individualised supports and services

This element includes incorporating a focus on the child's strengths and weaknesses, as well as family preferences, and the child and young person preferences and interests to determine the most appropriate intensity and level of instruction to meet their individual goals.

7–12 years	13–20 years
<b>Incorporating the child's preferences and special interests</b>	
It is possible to include the student's preferences and special interests into the learning objectives for teaching in almost any curriculum area in the primary area. It is particularly important that teachers consider the student's skills and preferences when asking students to demonstrate their learning (eg, the use of video and other technologies, rather than writing, which is often a difficulty).	At this level the actual content becomes more prescribed and more difficult to adapt. Therefore, teachers should: <ul style="list-style-type: none"> <li>• give students options, such as courses within their interest studied by correspondence</li> <li>• consider flexible ways for students to demonstrate their knowledge</li> <li>• work with students to give them the social understanding to be able to interpret the achievement criteria.</li> </ul>
<b>Individual attention to the child's needs to determine intensity and level of instruction</b>	
<ul style="list-style-type: none"> <li>• Provide professional learning and development for teachers so they are skilled and knowledgeable enough to make assessments to determine the student's needs and priorities.</li> <li>• Interventions should use the student's strengths and find accommodations for their weaknesses to allow them to participate as much as possible.</li> <li>• It is essential that the student's stress levels are monitored and that planned down time is incorporated into a programme where necessary.</li> </ul>	
Specialists and teachers need skills in writing appropriate, specific and achievable individual educational plans that focus on the key competencies. Goals need to be carefully thought out and planned step-by-step, and every person who works with the student needs to understand the purpose and the steps towards attaining the goals.	<ul style="list-style-type: none"> <li>• Students do not need a goal for every subject. The key goals can be adapted and generalised across all subject areas.</li> <li>• At a certain point, adaptive behaviours may need to become the priority.</li> <li>• Children and young people with ASD often suffer from fatigue. They may need to do fewer subjects than other students and have study periods in which to do their homework at school.</li> </ul>

## 2. Systematic instruction

This involves carefully planning for instruction by identifying valid educational goals, carefully outlining instructional procedures for teaching, implementing the procedures, evaluating their effectiveness and adjusting the instruction based on the evaluations.

7–12 years	13–20 years
Teachers and specialists require professional learning and development to have the expertise to target meaningful skills that need to be taught and to plan and implement systematic instruction and data collection.	
<ul style="list-style-type: none"> <li>Programmes need to set priorities with an emphasis on communication and social skills along with other ‘pivotal’ skills.</li> <li>It is important that all instruction is well considered and goal directed.</li> </ul>	<ul style="list-style-type: none"> <li>Curriculum adaptation is usually required, but there is often a tension about who will do this. This needs to be addressed. It is likely there will be different solutions for different students.</li> <li>Provision may need to be made for a number of teachers to receive release for professional learning and development.</li> <li>The emphasis needs to be on:               <ul style="list-style-type: none"> <li>the student’s understanding of the aim of the task</li> <li>getting step-by-step (visual) instructions</li> <li>the social, communication and cognitive elements being transparent</li> <li>student motivation and feedback.</li> </ul> </li> </ul>

## 3. Comprehensible and structured learning environments

This includes strategies such as organising the instructional setting, providing a schedule of activities that is kept up to date, carefully planning and providing choice-making opportunities, providing preventive behavioural support and providing supports to assist with transitions, flexibility and change.

7–12 years	13–20 years
Providing a comprehensible learning environment requires good planning, time to communicate with others, access to resources for making visual supports, and an understanding of and empathy with the student’s perspective.	This provides significantly more challenge at this level as students have multiple teachers, use different rooms and have different timetables. It is important that one person takes responsibility for coordinating what is required so that everyone understands the situation and has the right information. Students with ASD require clear boundaries and expectations. It is particularly important that students have a lot of support at the beginning of each year to learn the routines and rules, as well as the exceptions.

#### 4. Specific curriculum content

This component describes prioritising the core difficulties for individuals with ASD in the areas of communication and social interaction, and the skills that are required to participate.

7–12 years	13–20 years
<p>Children with autism need to be taught skills based on an individual assessment, with consideration for the family's preferences for targeting goals. Careful consideration should be given to the functionality of the skills, with an emphasis on skills that:</p> <ul style="list-style-type: none"> <li>• are most likely to be useful for the student to control his or her environment</li> <li>• will increase the student's independence and quality of life</li> <li>• will increase the student's competent performance.</li> </ul> <p>A goal for all students is to communicate effectively, even if the form is non-traditional.</p>	
<ul style="list-style-type: none"> <li>• There can be a tension in setting goals between the needs of the student and the needs of the teacher.</li> <li>• Communication and social interaction goals are clearly part of the key competencies in the New Zealand Curriculum. Teachers do not always have the skills to teach these competencies to children with ASD.</li> <li>• All specialists and teachers who work with students with ASD need to be given professional learning and development to help them take a long-term view of their students' needs and to be able to implement communication and social interaction teaching strategies such as contemporary ABA, augmentative communication, use of technology, PECS, pivotal response training, peer tutoring and social stories.</li> </ul>	<ul style="list-style-type: none"> <li>• If students have not mastered writing and other forms of traditional communication by this age, then quality of life and social validity issues become the priority.</li> <li>• Teachers and specialists need to work to find alternatives or accommodations that enhance participation in the student's environments.</li> <li>• It is particularly important that teachers continue to have high hopes for the students they work with and to continue to examine what the student can do and how their interests and the skills they have acquired can be enhanced or used to increase their motivation and ability to participate.</li> <li>• It is also crucial that there is continuity to any communication systems that have been established. This highlights the importance of good documentation of the student's skills, taking the time to observe and work with the student before transitions and information about the student (in the form of a profile) being kept up to date.</li> </ul>



## 5. Functional approach to problem behaviour

This describes the process by which the child's problem behaviour is not merely decreased or eliminated, but is replaced with an appropriate alternative or replacement behaviour that results in the same or similar consequences (*this is described in detail in section 3.2.e: Self-management skills and addressing challenging behaviour in education settings*).

Primary	Secondary
<ul style="list-style-type: none"> <li>Schools often have consequence-based behaviour management policies that can be in conflict with the functional behaviour principles and these need to be discussed and resolved.</li> <li>Teachers, principals and boards of trustees need to examine their policies and discuss the potential for conflict.</li> <li>The principles of functional behaviour assessment are not well understood by teachers and some specialists, and professional learning and development is needed.</li> </ul>	

## 6. Family involvement

Primary	Secondary
<p>Schools need:</p> <ul style="list-style-type: none"> <li>policies and practices that make parents feel welcome and encourage them to participate</li> <li>to support parents to get the information they need to make informed decisions</li> <li>to adopt and support effective home–school communication systems.</li> </ul>	
Systems are needed to help parents to learn about the curriculum, service provision and cross-sector initiatives.	Communication at this level tends to be less regular and often only one of the teachers (such as the SENCO) is involved. Very few individual educational plans include all teachers.

## Appendix 8: Educational interventions

### Background

The following educational programmes are currently being used within New Zealand or have an influence on other programmes currently in use. The list, however, is not exhaustive. These programmes have not been extensively reviewed in this guideline. It is intended that in-depth evaluations of particular programmes will occur in the future. This material has been drawn from the following references.<sup>104 137 437</sup>

### Educational programmes

#### **TEACCH (Treatment and Education of Autistic and Communication-Handicapped Children)**

This programme comes from Division TEACCH, at the University of North Carolina at Chapel Hill. The programme was developed by Eric Schopler and his colleagues in 1972. It has a behavioural base and uses aspects of naturalistic approaches. TEACCH is used widely in both the United States and other parts of the world. The significant features of the programme include the use of visual information to enhance comprehension and the provision of structure and predictability. Students are moved towards increasing independence.

Many of the strategies which are commonly used in New Zealand are based on those in the TEACCH programme, for example, visual supports. This programme is intended for use with children of all ages as well as adults.

#### **Early Intensive Behaviour Intervention (EIBI)/Intensive Behavioural Intervention (IBI)**

EIBI and IBI are generic titles for intensive and comprehensive behavioural programmes. The work of Ivor Lovaas at the University of California has been a strong influence on these programmes. Goals have a strong focus on developing language, cognitive skills, self-help skills and decreasing challenging behaviours. The intervention is usually delivered on a one-to-one basis in the child's home by parents or a therapist for 30 to 40 hours per week. A discrete trial format is typically used, especially in the beginning stages. Skills are broken into discrete steps and successes are reinforced.

#### **Naturalistic teaching approaches**

This approach includes programmes such as Incidental Teaching (developed by the Walden Early Childhood Programme) and Pivotal Response Training (developed by Koegel and Koegel).

These programmes were developed to increase generalisation of learning. Their theoretical base is applied behaviour analysis but they also draw on the parent-child interaction and developmental pragmatic literature. Activities are typically based around the child's interests and choices.

The Incidental Teaching programme includes children in classrooms with typically developing peers. Teaching is provided during regular activities. The focus is on the development of sustained engagement, functional verbal language, responsiveness to adults and peers and independence in daily living skills.

Pivotal Response Training focuses on the underlying skills to support learning such as self-motivation, responding to multiple cues and self-management with an aim for children to participate in inclusive education settings. Instruction involves some discrete trial teaching but moves towards more naturalistic methods.

### **Picture Exchange Communication System (PECS)**

Developed by Lori Frost and Andy Bond, PECS is a programme to teach the person to initiate communication. Symbols, pictures, photographs or objects are used by the child or adult to exchange for a desired object. Emphasis is placed on the very careful use of prompts and planned generalisation to foster independent communication.

The programme is highly structured and is based on the Applied Behaviour Analysis principles of stimulus, response and reward.

### **Denver Model**

The Denver Model is developmentally and behaviourally based and began as a demonstration programme at the University of Colorado Health Sciences Centre. In 1998 the centre-based programme was closed and intervention was provided in the natural environments of the home and early childhood centres with typically developing peers.

Play is used as primary vehicle for learning social, emotional, communication and cognitive skills. Techniques of functional behaviour analysis are used to identify and teach more appropriate alternative behaviours.

### **Learning Experiences, an Alternative Programme for Preschoolers and their Parents (LEAP)**

LEAP was developed as a university demonstration programme in Pennsylvania by Phillip Strain. It has since been incorporated into the Denver school system. The programme includes typically developing children and children with autism in classrooms for 15 hours per week. The child with ASD is included in typical classroom activities and the curriculum is supplemented with an individualised programme to support the development of functional skills, play and social and language skills. Peer-mediated teaching is used particularly for the development of social skills. Both ABA and developmentally based approaches are used.

### **Daily Life Therapy/Higashi School**

The programme was developed in the Higashi Schools in Tokyo and Boston. The aims are to instil dignity and independent living skills. The curriculum places an emphasis on developing physical strength and stamina through daily exercise. Music, art and drama are also a core part of the programme. Teaching is highly structured, intensive and focuses on group instruction.

### **SCERTS™ (Social Communication Emotional Regulation Transactional Supports)**

The SCERTS framework was developed by research collaborators Barry Prizant, Amy Wetherby, Emily Rubin and Amy Laurent and published in 2006. It is based on a variety of well-researched methodologies.

This comprehensive multidisciplinary model addresses the key challenges faced by children with ASD. Intervention goals focus on the development of spontaneous communication, teaching and supporting the child to regulate their emotional state and providing supports to the child, the family and the professionals working with the child (transactional supports). Teaching goals are embedded in the natural contexts and routines of the child and family. Practices from a variety of approaches are incorporated into the model including behavioural and developmental approaches.

### **Social stories**

Social stories were developed by Carol Gray. They involve written or drawn stories which explain social situations and sometimes contain suggestions for socially appropriate responses. The stories are individualised for each person and can be used with both children and adults.

### **Developmental Individual Difference Relationship-based model (DIR)/'Floortime'**

This model was developed by Stanley Greenspan at the National Centre for Clinical Infant Programs in the United States. The developmentally based model has a focus on building relationships, communication and thinking as the basis for future development. The model is used with young children and has an emphasis on interactive play where an adult follows the child's lead in activities and interactions.

### **Relationship Development Intervention (RDI)**

The model was developed by Steven Gutstein at the Connection Centre. RDI is a developmentally based, relationship model. The aim is to increase the child's interest and motivation in relating with others. Many activities and strategies are

recommended which support social development. The role and style of interactions of the 'partner' are a key element.

### **Options Programme/Son-Rise**

The Options method was developed by Barry and Samahria Kaufman in the 1980s as a means of working with their son. The aim is to develop communication and relationships as the basis for future learning. This intensive home-based programme is delivered primarily by the parents in an environment which is as distraction-free as possible. The adults follow the child's lead and join in preferred activities. When the child is attentive, the adult expands on the activity and attempts to encourage interactions. Parents are trained to alter the manner in which they interact with the child and to become more accepting of their activities and behaviours.

### **Parent-focused programmes**

#### **Hanen 'More than Words'**

'More than Words' is an autism-specific parent education programme developed by the Hanen Centre in Toronto, Canada. Its aim is to teach parents to facilitate functional communication in their young children through embedding learning in everyday activities and routines. It is based on social pragmatic developmental and behavioural principles. Parents are taught the strategies in groups. Feedback and coaching are also given to parents in their own homes through reviewing videotapes of parent-child interactions. There is an emphasis on the use of structure and visual supports to enhance the child's learning.

### **EarlyBird**

Earlybird was developed by the National Autistic Society in Britain. Its aim is to support parents of children under five who have autism in the development of general management strategies and particularly with social communication and the development of appropriate behaviours. Parents meet in group teaching sessions. They are also supported through home visits where videos of the parent interacting with his or her child are discussed.

Other parent focused programmes developed by the National Autistic Society are 'Spell' and 'Help!' for children five years and over.

### **Programmes based on the creative arts**

#### **Music therapy**

Music therapy uses music in a planned and creative manner to promote good health and to address physiological, emotion, cognitive and social needs through the development of a therapeutic relationship.<sup>137</sup> Music therapy has also been promoted as an effective treatment in facilitating communication by offering a means by which alternative communication can be established to help achieve engagement, interaction and relationships.<sup>438</sup>

At present, the evidence for the effectiveness of music therapy is unclear.<sup>438</sup> Standardised models of assessment in music therapy should be considered for future development. No large scale randomised control trial involving young children with autism has been conducted. With this level of evidence, broad claims about the universal effectiveness of music therapy for all children with autism must be met with caution and tested through studies with appropriate design and methodological rigour.<sup>137</sup>

#### **Creative arts and drama therapy**

Dramatherapy focuses on the healing powers of drama, movement and theatre as it integrates the mind, emotions and physical body. The therapy encourages creativity and imagination for learning, insight and growth. Dramatherapy can also support the person to learn how to manage social situations.<sup>439</sup>

At present, the evidence for the effectiveness of both creative arts and drama therapy is unclear. More research in the form of well-designed primary randomised controlled studies of creative arts and drama therapy is recommended.

## Appendix 9: Drugs used in ASD

Please note this is intended as a guide only. Clinicians should consult other appropriate references for comprehensive information on adverse effects and interactions.

**Table 9.1: Drugs used in ASD (adapted with permission from CAMHSNET)<sup>440</sup>**

Generic name	Trade name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
<b>Atypical Antipsychotics</b>					
Risperidone	Risperdal	Oral liquid: 1mg/ml Tablet: 0.5mg, 1mg, 2mg, 3mg, 4mg Orally disintegrating tablets: 0.5mg, 1mg, 2mg (Special Authority criteria apply) Retail pharmacy – Specialist Fully subsidised	0.015mg/kg/day to 0.05mg/kg/day in two divided doses	<ul style="list-style-type: none"> <li>• Weight gain</li> <li>• Extrapyramidal side effects [EPSE] (worse at higher dosage)</li> <li>• Akathisia (esp. adolescents)</li> <li>• Sedation</li> <li>• Insomnia</li> <li>• Type 2 diabetes mellitus</li> <li>• Sialorrhoea</li> <li>• Enuresis, rhinitis, epistaxis</li> <li>• Sexual dysfunction, priapism</li> </ul>	Carbamazepine (↓ levels of RISP) SSRIs (↑ levels of RISP and SSRI) unlikely clinically significant but watch for serotonin toxicity
Olanzapine	Zyprexa	Tablet: 2.5mg, 5mg, 10mg Orodispersible wafer 5mg, 10mg Retail pharmacy – Special Authority – application only by Psychiatrist Fully subsidised	0.1 to 0.25 mg/kg/day in 2 divided doses. Max 20mg per day in adolescents >40kg	As for risperidone, but weight gain and type 2 diabetes more likely and EPSE less likely.	

Generic name	Trade name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
Quetiapine	Seroquel	Tablet: 25mg, 100mg, 150mg, 200mg See prescribing advice in Pharmaceutical Schedule. Fully subsidised	0.25 to 8 mg/kg/day in 2 divided doses	As for risperidone. Agitation commonly reported in adults.	
<b>Typical antipsychotics</b>					
Haloperidol	Serenace	Oral liquid: 2mg/ml Tablet: 500mcg; 1.5mg; 5mg Also injection Retail pharmacy Fully subsidised	0.01 to 0.2 mg/kg/day in 2 divided doses Max 10mg/day	<ul style="list-style-type: none"> <li>• EPSE very common</li> <li>• Tardive and withdrawal dyskinesias</li> <li>• Sedation</li> </ul>	Lithium SSRIs (↑ level of haloperidol) Ginseng
Chlorpromazine	Largactil	Tablet: 10mg; 25mg; 100mg Also injection Retail pharmacy Fully subsidised	0.25 to 5 mg/kg/day in 4 divided doses	<ul style="list-style-type: none"> <li>• Sedation</li> <li>• Photosensitive rash</li> <li>• EPSE</li> <li>• Seizures, jaundice, agranulocytosis, cardiotoxicity (arrhythmias)</li> </ul>	Propranolol Valproate
Thioridazine	Aldazine Melleril	Tablet: 10mg; 25mg; 50mg; 100mg Retail pharmacy Fully subsidised		<ul style="list-style-type: none"> <li>• Cardiac arrhythmias</li> </ul>	Safer alternatives available.

Generic name	Trade name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
<b>Selective serotonin re-uptake inhibitors (SSRIs)</b>					
Fluoxetine	Fluox Prozac	Tablet dispersible: 20mg Capsule: 20mg Retail pharmacy Fluox brand fully subsidised	0.15 to 0.6 mg/kg/day as a single dose	<ul style="list-style-type: none"> <li>• Agitation, behavioural disinhibition</li> <li>• Dry mouth</li> <li>• Drowsiness</li> <li>• Nausea, weight loss</li> <li>• Lowered seizure threshold</li> </ul> <b>Serotonin toxicity in overdose</b>	Wide range of drugs St John's Wort <b>Risk of serotonin toxicity with other serotonergic drugs</b>
Paroxetine	Loxamine Aropax	Tablet: 20mg Retail pharmacy Loxamine brand fully subsidised	0.2 to 0.5 mg/kg/day in 2 divided doses	As for fluoxetine. Possible increase in suicidal ideation in adolescents.	<b>Risk of serotonin toxicity with other serotonergic drugs</b>
Citalopram	Arrow Citalopram Celapram Citalopram-Rex Cipramil	Tablet: 20mg Retail pharmacy Some brands fully subsidised	0.2 to 0.4 mg/kg/day as a single dose	More selective, therefore fewer adverse effects.	Other SSRIs Venlafaxine MAOIs Buspirone MDMA (ecstasy) as high risk of <b>Serotonin toxicity</b>
Sertraline	Zoloft	Not funded in New Zealand	0.5 to 3 mg/kg/day as a single dose	<ul style="list-style-type: none"> <li>• Insomnia</li> <li>• Nausea</li> <li>• Headache</li> <li>• Agitation</li> </ul> These are all common.	Tricyclic antidepressants and a wide range of drugs. <b>Risk of serotonin toxicity with other serotonergic drugs</b>



Generic name	Trade name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
<b>Stimulants</b>					
Methylphenidate	Rubifen Ritalin Concerta	Tablet: 5mg, 10mg, 20mg (immediate release – IR) – Rubifen Tablet: 20mg long acting – RubifenSR, RitalinSR Retail Pharmacy Special Authority – for full details see PHARMAC website. Only brands noted above are fully subsidised. Additional criteria apply for RitalinSR brand. Class A controlled drug.	Start low 2.5mg to 5mg per day as morning dose. Can increase up to 1 mg/kg/day Max dose 60mg per day	<ul style="list-style-type: none"> <li>• Anorexia</li> <li>• Irritability and emotional lability</li> <li>• Insomnia</li> <li>• Exacerbation of tic disorder</li> <li>• Rebound hyperactivity</li> <li>• Exacerbation of repetitive or obsessional behaviour</li> </ul>	Carbamazepine Previous concerns about interaction with Clonidine have not been proven.
Dexamphetamine		Tablet: 5mg Retail Pharmacy Special Authority – for full details see PHARMAC website. Fully subsidised. Class A controlled drug.	Start low 1.25mg to 2.5mg per day as morning dose. Can increase up to 1 mg/kg/day. Max dose 30mg per day	<ul style="list-style-type: none"> <li>• Anorexia</li> <li>• Irritability and emotional lability</li> <li>• Insomnia</li> <li>• Exacerbation of tic disorder</li> <li>• Rebound hyperactivity</li> <li>• Exacerbation of repetitive or obsessional behaviour</li> </ul>	<ul style="list-style-type: none"> <li>• Acetazolamide</li> <li>• Sodium bicarbonate</li> </ul>
<b>Other drugs</b>					
Clonidine	Catapres Dixarit	Tablet: 25mcg (Dixarit); 150mcg (Catapres) Transdermal systems: 100mcg, 200mcg and 300mcg per day Retail pharmacy Fully subsidised	2 to 5 micrograms/kg/day Start with once daily dose. Twice daily as dose increased	<ul style="list-style-type: none"> <li>• Sedation</li> <li>• Hypotension (<b>Monitor blood pressure</b>)</li> <li>• Depression</li> <li>• Withdrawal hypertension (taper over 6 days)</li> <li>• Precocious puberty – rare</li> </ul>	Previous concerns about interaction with Methylphenidate have not been proven.

Generic name	Trade name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
Benztropine	Benztrop Cogentin	Tablet: 2mg (Benztrop) Also injection (Cogentin) Retail pharmacy Fully subsidised	0.02 to 0.03 mg/kg/dose	<ul style="list-style-type: none"> <li>• Sedation</li> <li>• Headache</li> <li>• Nausea</li> <li>• Confusion</li> </ul>	Used to treat EPSE.
Trimeprazine	Vallergan	Oral liquid: 30mg/5ml Retail pharmacy Partial subsidy			
Promethazine	Phenergan Avomine Allersoothe	Oral liquid: 5mg/5ml Tablet: 10mg; 25mg Retail pharmacy Part subsidy on liquid Fully subsidised tablet formulations			
Melatonin		Not funded in New Zealand. A range of formulations is available from retail pharmacies.			

**Note:** Information is correct at time of writing. Brands available and subsidy status are under constant review. Prescribers should check current information on the PHARMAC ([www.pharmac.govt.nz](http://www.pharmac.govt.nz)) and MEDSAFE ([www.medsafe.govt.nz](http://www.medsafe.govt.nz)) websites.

## Appendix 10: Summaries of Living Guideline Group Supplementary Papers

### 10.1 Summary of Supplementary paper on Applied Behaviour Analysis

The full Supplementary Paper describing the Living Guideline Group's (LGG) modified recommendations from the guideline's first edition, and newly developed recommendations and good practice points, is available from the Ministry of Health website.<sup>12</sup> Supporting evidence reviews can be downloaded from other online sources.<sup>441–443</sup>

#### Preamble

As a result of feedback received during consultation for the first edition of the guideline, the Ministry of Health and Ministry of Education sought additional review work on published research on interventions and strategies based on applied behaviour analysis (ABA) in relation to outcomes for people with ASD. Following an open tendering process, the Ministry of Education funded two groups to critically appraise the relevant literature:

- (i) the New Zealand Guidelines Group (NZGG),<sup>441</sup> and
- (ii) a consortium of New Zealand academics with expertise in ABA, led by Dr Oliver Mudford at the University of Auckland.<sup>442</sup>

These technical reviews, conducted independently and in parallel, were peer reviewed, subsequently revised and presented to the ASD cross-government Senior Officials Group in February 2009.

#### Living Guideline Group process

A living guideline process was set up to keep the NZ ASD Guideline current and a Living Guideline Group (LGG) was convened by NZGG to carry out this process. The first topic considered by the LGG was ABA. As the two technical reviews referred to above were based on research published to December 2007, a review update of additional high level secondary evidence (systematic reviews) published to August 2009 was undertaken.<sup>443</sup> This review update and the two technical reviews were considered by an independent technical expert, Professor Margot Prior (University of Melbourne).

The LGG held a two-day meeting to consider the evidence from the two literature reviews on ABA, the update of more recently published ABA reviews, and Professor Prior's summary comments.

#### Additional notes

Definitions of ABA and Early Intensive Behavioural Intervention (EIBI) are important for this review, and are provided in the Glossary.

Readers should take note of the recommendations in the guideline particularly relevant to interventions based on ABA: Recommendations 3.1.5, 3.2.5.3, and 4.3.3. Legislation, standards and policies highlighted in the guideline are also relevant, including the United Nations Convention for the Rights of Persons with Disabilities (2008).

### Review of ABA evidence and impact on recommendations

Unchanged recommendations	Grade
<p><b>3.2.5.2</b> Educational interventions should incorporate principles of positive behaviour support, particularly a focus on understanding the function of the child's behaviour.</p> <p><b>Additional text:</b> The use of the term positive behaviour support in the NZ ASD guideline has caused confusion due to the implication that it might refer to a different, specific intervention package in ASD called 'Positive Behaviour Support.' For an understanding of positive behaviour support as a general set of professional standards and values, see discussion under section 3.2.e under "positive behaviour supports" of the NZ ASD guideline.</p> <p><b>Rationale:</b> General agreement that Recommendation 3.2.5.2 and its grade are accurate and should remain unchanged, but supporting text is needed to define what is meant by positive behaviour support to avoid any ambiguity.</p>	A

Revised recommendations	Grade
<p><b>4.3.4</b> Behaviour management techniques should be used to intervene with problem behaviours.</p> <p><i>Changed to:</i></p> <p><b>4.3.4</b> Behaviour management techniques should be used to intervene with problem behaviours following functional behaviour assessment.</p> <p><b>Rationale:</b> The addition of the phrase 'following functional behaviour assessment' at the end of the recommendation is supported by evidence relating to functional behaviour assessment both in the NZ ASD guideline (section 4.3.a, and Recommendation 4.3.5) and by the new evidence presented to the LGG. The importance of conducting a functional analysis prior to conducting interventions with challenging behaviour was implied in the original recommendation but needed to be made explicit. There was agreement that the grade of A does not need to change.</p>	A

Revised recommendations	Grade
<p><b>4.3.6</b> Consumers of behavioural interventions should refer to recently published guidelines for identifying, selecting and evaluating behaviour analysts with people with ASD.</p> <p><i>Changed to:</i></p> <p><b>4.3.6</b> Consumers of applied behaviour analysis interventions should refer to recently published guidelines for identifying, selecting and evaluating behaviour analyst services for people with ASD.</p> <p><b>Rationale:</b> Changed behavioural to applied behaviour analysis to be more explicit about the recommendation being linked with considered ABA evidence.</p> <p>Note that the guidelines are those referred to in reference 292 of this guideline.</p> <p>The LGG decided no further supporting text is needed as the guideline provides a rationale and outlines qualifications and training issues relevant to ABA.</p> <p>Also decided to reword for clarity with the addition of ‘services for’.</p>	C

New recommendations	Grade
<p><b>4.3.5a</b> Interventions and strategies based on applied behaviour analysis (ABA) principles should be considered for all children with ASD.</p> <p><b>Additional text:</b> ABA does not refer to one programme or technique.</p> <p>In the evidence considered by the LGG, there was little or no New Zealand-based research showing the appropriateness of ABA to the New Zealand context and population.</p> <p>There is a lack of knowledge about the suitability of ABA for persons with an Asperger Syndrome diagnosis, and for participants aged 15 years or above.</p> <p><b>Rationale:</b> The LGG decided to use ‘based on ABA principles’ to make connection with research evidence around ABA explicit as many interventions include behavioural components.</p> <p>The LGG decided to use the term ASD as consistent with terminology used in NZ ASD Guideline.</p> <p>Agreed that the phrase ‘interventions and strategies’ encompasses a range of approaches, as explained in the definition of ABA offered in the Glossary.</p>	A

New recommendations	Grade
<p><b>4.3.5b</b> Early intensive behavioural intervention (EIBI) should be considered as a treatment of value for young children with ASD to improve outcomes such as cognitive ability, language skills, and adaptive behaviour.</p> <p><b>Additional text:</b> There is substantial individual variability in outcomes ranging from very positive improvements, through minor or minimal improvements, to no effects. Families need to be advised of this conditional evidence about treatment outcomes.</p> <p>We still cannot specify which attributes of participants, families, treatment methods etc., are critical to outcome, apart from findings that higher IQ and language competence in individuals at the pre-treatment stage are predictive to some extent of greater gains post treatment, and at longer follow up.</p> <p>There is as yet insufficient research comparing high quality intensive ‘other’ treatment with EIBI to allow comparative judgements of treatment effectiveness.</p> <p>There is a lack of knowledge about the suitability of EIBI for the diverse ethnic and cultural groups of New Zealand and for people with a diagnosis of Asperger Syndrome.</p> <p>Individual trajectories in progress are the norm. Research suggests substantial individual variability in outcomes, ranging from very positive improvements, through minor or minimal improvements, to no effects found. Regular monitoring and evaluation of intervention effectiveness is therefore crucial (refer to Recommendations 3.1.5 and 4.3.3).</p> <p><b>Rationale:</b> Uncertainty about the optimal intensity of hours, and who it benefits, is reflected in the grade allocated to this recommendation.</p> <p>As evidence relating to spontaneous, social communication competencies is equivocal, the recommendation refers to language skills.</p>	B

New good practice points	Grade
<p><b>4.3.11</b> Applied behaviour analysis (ABA) interventions and strategies should be relevant to the child’s context and culture</p> <p><b>Rationale:</b> The need to weave cultural sensitivity throughout the NZ ASD guideline was agreed as important at the first LGG meeting.</p>	✓
<p><b>4.3.12</b> Interventions based on the principles of ABA can be introduced before the diagnosis of ASD is confirmed in a child displaying some of the symptoms of ASD.</p> <p><b>Rationale:</b> There was a concern about issues relating to diagnosis as some people have a delay in diagnosis which could delay effective treatment.</p> <p>Recommendation 3.1.1 supports this good practice point:</p> <p>‘Services should not wait for the diagnostic process to be completed but should be available as soon as a significant developmental need is identified.’ (Grade C)</p>	✓

## 10.2 Summary of Supplementary paper on Pharmacotherapies

The full Supplementary Paper, describing the Living Guideline Group's (LGG) modified recommendations from the first edition of guideline, and newly developed recommendations and good practice points, is available from the Ministry of Health website.<sup>13</sup> The supporting systematic review can be downloaded from another online source.<sup>444</sup>

### Preamble

ASD can be associated with substantial impairment and people with ASD and/or their caregivers can be particularly vulnerable to trying pharmacological treatments without solid supporting evidence. It is therefore crucial that clinicians provide consumers with clear information about the limits of the evidence available, the potential for side effects and adverse events, and alternatives open to them.

### The Living Guideline Group process

The Living Guideline Group considered updated evidence relating to three pharmacological interventions for people with ASD: the atypical antipsychotic aripiprazole, the selective serotonin reuptake inhibitor (SSRI) citalopram, and the hormone, melatonin.

The NZGG conducted a systematic review updating evidence from the NZ ASD Guideline on these three pharmacological agents.<sup>444</sup> Any controlled study assessing effectiveness was eligible for inclusion, as well as systematic reviews of the interventions. Assessment of the updated evidence relevant to the three pharmacological interventions resulted in a number of revised and new recommendations.

### Aripiprazole

There is currently no mention of aripiprazole in the ASD Guideline. Eight studies were critically appraised in the review update: six systematic reviews and two randomised controlled trials.

The LGG discussed the relative advantage of aripiprazole over risperidone in terms of its side effect profile, especially with respect to weight gain. It was agreed that aripiprazole may be a potentially effective alternative to the first line atypical antipsychotic risperidone where this medication has not been effective or where significant metabolic or adverse effects have arisen, or are likely to arise. However it was noted that there has been no comparative or head-to-head study of aripiprazole with risperidone or other agents from its class.

While the mechanism of action of aripiprazole is unclear, it was acknowledged that this is also the case for other antipsychotics.

The LGG agreed that the evidence suggests a cautious approach to the use of aripiprazole at the present time. Lower initial and target doses are advisable for those most vulnerable to side effects, including children, and particularly in the treatment of irritability and aggression in people with PDD. Ongoing monitoring of metabolic parameters is also recommended, including weight or body mass index, pulse, blood pressure, glucose and lipid metabolism, and possibly serum prolactin.

As the possibility of aripiprazole causing tardive dyskinesia cannot be excluded, baseline and periodic testing using the Abnormal Involuntary Movements Scale (AIMS) was highlighted. The LGG noted that aripiprazole should be initiated within the care of secondary care clinicians.

The LGG advise that careful consideration, informed consent and ongoing monitoring is necessary before this medication is considered as a first-line treatment in people with ASD.

Revised recommendations	Grade
<b>4.4.4</b> There is insufficient evidence to make any specific recommendation regarding atypical antipsychotic agents other than risperidone. Clinicians prescribing these drugs need to keep up to date with current literature.	I
<i>Changed to:</i>	
<b>4.4.4</b> In most circumstances risperidone should be the first medication used when indicated for significant irritability in children and young people with ASD. Aripiprazole could be used as a second-line treatment where individuals have demonstrated poor efficacy to risperidone or where there is concern regarding significant metabolic or adverse effects. Clinicians prescribing these drugs need to keep up to date with current literature.	B

## Citalopram

Citalopram is included in Appendix 9 of this Guideline (Table 9.1) as an SSRI used in NZ for people with ASD.

The review update identified preliminary open-label trials of the use of citalopram, for people with ASD, two good quality systematic reviews, and a high quality multi-centre, triple blinded study of 149 children and adolescents.

The LGG recognise that repetitive behaviours are not always a concern for a person with ASD, and that it is important to determine the interference of the behaviour with daily functioning, harm to self and others, and distress, when assessing the need for intervention.

The LGG discussed whether there may be a class effect generally with SSRIs, in view of the conclusions of a Cochrane review.<sup>445</sup> However as the current NZGG review focused on the role of citalopram alone, this was outside the scope of the LGG's guidance.

The LGG concluded that the balance of evidence for benefit and harm at a clinical level was such that citalopram could not be currently recommended for the pharmacological treatment of repetitive behaviour in children and young people with ASD. Caution was also urged in its use for established comorbid indications in this population, given the evidence of adverse events.

It should be noted that the study sample upon which the new recommendations were developed were children and adolescents. Whilst the review update was not restricted in its scope to younger people, unfortunately there is a lack of new research in adult populations. Caution is necessary in translating results from one age/developmental group to another, hence the specification of children and young people in the new recommendations relating to citalopram.



Revised recommendations	Grade
<b>4.4.1a</b> Citalopram cannot currently be recommended for the treatment of repetitive behaviours in children and young people with ASD.	B
<b>4.4.1b</b> Citalopram's use for established comorbid indications for children and young people (eg, anxiety, obsessive compulsive disorder) should be considered with significant caution on a case-by-case basis, after full disclosure of side effects to the individual and their family and careful ongoing monitoring.	C

## Melatonin

The review update appraised four systematic reviews, and one cross-over trial of good quality.

The LGG agreed that Recommendation 4.4.7 should be strengthened in view of the updated evidence. It is important to consider the level of impairment to quality of life as a function of sleep problems, for the individual and their family, in deciding whether to use melatonin.

There is as yet no consensus on the therapeutic dose of melatonin for children and adolescents. The studies cited have generally used a 5mg dose, however the LGG suggested that in clinical practice it is appropriate and useful to initiate with lower doses, of 1 or 2 mg. There was a suggestion that controlled release melatonin is not always practical for children with ASD, as many children with ASD are not able to swallow tablets or capsules whole, but it may have advantages over fast-release formulations for those children who have trouble sustaining sleep.

The LGG note that the evidence has a number of limitations. There are few controlled trials. There are no long-term investigations of melatonin, with the longest follow-up in controlled studies being one month. In one small open-label study<sup>446</sup> extending over two years, improved sleep appeared to be maintained at 12- and 24-month follow-up but sleep problems returned for 16 of 25 children when melatonin was discontinued. Such findings suggest that sleep difficulties can be a chronic problem requiring ongoing treatment. The benefits and side effects of longer-term treatment require further investigation under controlled conditions. This need is captured in the development of a new research recommendation. As for citalopram, the evidence base is predominantly derived from children and young people, and its applicability to adults is uncertain.

Given these uncertainties, the LGG recommended caution in the administration of melatonin over the longer term, and that behavioural strategies including improvements to sleep hygiene should also be attempted in parallel with melatonin. Sleep hygiene is the regulation of daily activities and environmental factors aimed at maintaining good quality sleep and daytime alertness. Strategies might include having a quiet bedroom, employing a regular sleep time schedule, and the avoidance of stimulants and late night recreations.

Revised recommendations	Grade
<p><b>4.4.7</b> Melatonin may be useful for improving sleep in children with ASD who have impaired sleep.</p> <p><i>Changed to:</i></p> <p><b>4.4.7</b> Melatonin can be recommended for use in children and young people with ASD who are experiencing significant sleep problems.</p>	B

New recommendations	Grade
<b>4.4.7a</b> Benefits and adverse effects of longer term treatment of melatonin require further investigation.	C
<b>4.4.7b</b> Behavioural strategies (eg, sleep hygiene) should always be used in conjunction with melatonin.	C

### 10.3 Summary of Supplementary paper on Supported Employment

The full Supplementary Paper, describing the Living Guideline Group's (LGG) modified and newly developed recommendations and good practice points, and the supportive systematic review, is available from the Ministry of Health website.<sup>14</sup>

#### Preamble

Supported employment are formal programmes providing ongoing support (flexible, individualised, for an indefinite time) to find and maintain real paid work (paid at no less than market pay rates and under standard conditions) in 'integrated' settings alongside people without disabilities. In some conventions, minimum hours of employment may be specified (eg, at least 16 hours per week) or minimum periods of employment. Less comprehensive forms of assistance which do not provide ongoing on-the-job support are termed *employment supports*. Employment supports, and more specifically supported employment, can be offered by employment services as described in the guideline.

Supported employment is to be distinguished from *sheltered employment* where people work alongside other people with disabilities in a segregated, specially tailored settings and are commonly paid below market-rate wages.

People with ASD are often disadvantaged in the competitive job market in finding, applying for, securing and keeping real, paid jobs. Poor employment outcomes including unemployment, and under-employment, have led to the development of supported employment services. These provide ongoing support (flexible, individualised, and for an indefinite time) to find and maintain real work (paid at no less than market pay rates and under standard conditions) in 'integrated' settings (ie, alongside people without disabilities).

## The Living Guideline Group process

The Living Guideline Group considered a systematic review on the effectiveness of supported employment services for young people and adults (aged 16 years or over) with ASD<sup>14</sup> which updated evidence from the NZ ASD Guideline on this topic. The appraised body of evidence consisted of eight separate studies: two systematic, largely narrative reviews, and six primary studies: four case series studies, a non-randomised experimental trial, and a cohort study.

Revised recommendations	Grade
<p><b>5.1.9</b> Known support needs of people with ASD who also have an intellectual disability should be taken into account when transitioning into any work environment.</p> <p><i>Changed to:</i></p> <p><b>5.1.9</b> Any known support needs of people with ASD, including those relating to cognitive ability, should be taken into account when transitioning into any work environment.</p> <p><b>Rationale:</b> The updated evidence indicated that all people with ASD need their support needs considered, not just those with intellectual disability. The LGG was concerned that the recommendation implied that only those with intellectual disability have any known support needs considered. The revised wording refers to any known support needs for all people with ASD but also identifies cognitive ability as one area that may need to be taken into account in assessing support needs. It is also acknowledged that some people with ASD may not have support needs requiring intervention from a supported employment service. Cognitive ability was considered by the group to be the more relevant and specific term.</p>	B
<p><b>5.1.10</b> Specialist employment services for people with ASD should be developed.</p> <p><i>Changed to:</i></p> <p><b>5.1.10</b> Supported employment services for people with ASD should be developed</p> <p><b>Rationale:</b> the term “supported employment services” is used to refer to the services described as specialist employment services in the ASD Guideline.</p>	C
<p><b>5.1.11</b> Specialist Employment Services should incorporate both known features of best practice employment for people with an intellectual disability and ASD-specific strategies.</p> <p><i>Changed to:</i></p> <p><b>5.1.11</b> Supported employment services should incorporate known features of best practice employment for people with an intellectual disability and ASD-specific strategies.</p> <p><b>Rationale:</b> Minor changes were made for improved readability and consistency with other recommendations and terminology.</p>	B

Revised recommendations	Grade
<p><b>5.1.12</b> Symptoms of ASD that may have impact in the work setting (both as strengths and as needs) should be taken into account when planning transition into work, and when making choices about work and career.</p> <p><i>Changed to:</i></p> <p><b>5.1.12</b> Any characteristics of ASD that may have impact in the work setting (both as strengths and as needs) should be taken into account when planning transition into work, when making choices about work and career and in accessing ongoing in-work support.</p> <p><b>Rationale:</b> Changed ‘symptoms’ to ‘any characteristics’ in line with the positive framework the guideline takes for people with ASD and the recognition that characteristics of ASD vary widely across individuals. Also added ‘in providing in-work support’ to broaden this recommendation to considering support provided at the workplace, which is a key component of successful supported employment services. Grade also changed from C to a B to reflect updated evidence with respect to supported employment.</p>	<p>C</p> <p>B</p>
<p><b>5.1.13</b> Specialist employment services should work with workplace supervisors to maximise success in work placements.</p> <p><i>Changed to:</i></p> <p><b>5.1.13</b> Supported employment services should work with employers, managers and colleagues to maximise success in work placements.</p> <p><b>Rationale:</b> Changes were made to ensure consistent terminology. The wording was changed to refer to workplace personnel more broadly and not just supervisors.</p>	<p>B</p>

**Note:** Recommendation 5.1.8 was considered out of scope of the evidence considered and remained unchanged. In the absence of any additional evidence, good practice points 5.1.15 and 5.1.16 remain unchanged.

New recommendations and Good Practice Points	Grade
<p><b>5.1.13a</b> Supported employment services are recommended and should be available for all people with ASD.</p> <p><b>Rationale:</b> By recommending supported employment for all people with ASD, the LGG observed that the evidence supports the efficacy of supported employment compared with no supported employment or less intense forms of employment supports. However the LGG recognise that, as with many services, it will not lead to 100% success and people with ASD continue to experience inequity in employment.</p>	<p>B</p>

New recommendations and Good Practice Points	Grade
<p><b>5.1.13b</b> ‘Supported employment services should make available, where required:</p> <ul style="list-style-type: none"> <li>• Individualised job matching based on the person’s career goals, strengths, and interests</li> <li>• Pre-placement assessment of work tasks and work environment</li> <li>• Promoting understanding of any support needs within the work environment, including training employers and colleagues in the goals, processes and benefits of supported employment services.</li> <li>• On-the-job provisions, including training of work tasks, acclimatisation to the work environment, social integration, developing communication and interpersonal skills, and management of stress and any contextually inappropriate behaviour</li> <li>• Job coaches with level of support is determined by need</li> <li>• Workplace modifications</li> </ul> <p>Long-term support in developing natural supports (eg, upskilling managers) and, where needed, external supports (eg, follow-up, assisting with issues which impact on work).</p> <p><b>Rationale:</b> The group specified the key characteristics of successful supported employment services identified in the review update. These features are recommended as being ‘made available where required’ to reflect that services should reflect what is required and requested by the client with ASD. Recommendation 5.1.13.b. emphasises that the workplace and staff need to consider how they may need to adjust to support the needs of a worker with ASD and the benefits of having a diversity of staff in the workplace. The LGG noted that the term ‘inappropriate behaviour’ (Recommendation 5.1.13b) was used in the literature to specifically refer to behaviour deemed by the employer to be inappropriate in that particular workplace. Management can include changes made by the supported worker, co-workers and/or the workplace. Follow-up refers to the job coach checking in with the supported worker regularly via site visits and phone-calls to identify any problems and provide ongoing support.</p>	B
<p><b>5.1.13c</b> Methodologically rigorous research is greatly needed to examine and improve the effectiveness of New Zealand-based supported employment services for people with ASD.</p> <p><b>Rationale:</b> As part of the systematic review update a wide search of grey literature in New Zealand was conducted. Whilst many supported employment services were identified, no evaluations were found which met inclusion criteria.</p>	✓
<p><b>5.1.13d</b> New Zealand based research should consider the effectiveness of supported employment services for people of different ethnicities with ASD.</p> <p><b>Rationale:</b> Research from one large cohort study indicated that employment rates for clients receiving supported employment services varied as a function of ethnicity such that rates were lower for people identifying themselves as African American.<sup>33</sup> Ethnicity is likely to be an important factor in the success of supported employment services in New Zealand also and worthy of future research reflecting the diversity of the local population.</p>	✓

## 10.4 Summary of Supplementary paper on Gastrointestinal Issues

The full Supplementary Paper, describing the Living Guideline Group's (LGG) modified and newly developed recommendations and good practice points, and the supportive systematic review, is available from the Ministry of Health website.<sup>15</sup> This document needs to be read in context of the recommendations in the ASD Guideline that all children with ASD to undergo a comprehensive health and developmental assessment.

### Preamble

Gastrointestinal (GI) problems may be more common in ASD than in the general population. The reasons why some conditions may occur more commonly in people with ASD is not well understood.<sup>11</sup> Whilst GI problems arising in people with ASD may have the same causes as GI problems in people without ASD, some researchers have suggested that people with autism are especially susceptible to gastrointestinal dysfunction.

*Gastrointestinal problems* refer to dysfunction that is evident in clinical symptoms, usually chronic, persistent, recurrent, frequent or excessive in nature, which do not have clear anatomic, metabolic, or pathologic process. These problems may include the following:

- chronic constipation
- diarrhoea, faecal incontinence, encopresis (faecal soiling), changes to bowel habit
- vomiting, nausea, gastroesophageal reflux (GER)
- abdominal pain, discomfort, irritability, bloating, flatulence.

It should be noted that encopresis might be a symptom of constipation.

### The Living Guideline Group process

The Living Guideline Group considered a systematic review of evidence relating to gastrointestinal (GI) problems in children and young people (aged 18 years or under) with ASD<sup>15</sup> which updated evidence from the first edition of the NZ ASD Guideline on this topic.

The appraised body of evidence consisted of 14 studies, including three systematic reviews, three retrospective cohort studies and eight cross-sectional behavioural studies.

Revised recommendations	Grade
<p><b>4.6.1</b> When challenging behaviours are evident, people with ASD need to be assessed for co-morbid conditions such as seizures, ADHD, anxiety disorders and depression.</p> <p><i>Changed to:</i></p> <p><b>4.6.1</b> When challenging behaviours are evident, people with ASD need to be assessed for co-morbid conditions such as seizures, ADHD, anxiety disorders, depression, and gastrointestinal problems.</p> <p><b>Rationale:</b> Challenging behaviour may be the primary or sole symptom of gastrointestinal problems. This evidence is based on consensus expert opinion and cross-sectional studies.</p>	C

**Note:** Recommendation 2.3.9 and 4.1.4 remain unchanged.

New recommendations	Grade
<p><b>4.1.4a</b> Gastrointestinal problems, specifically constipation, chronic diarrhoea, altered bowel habits, and encopresis (faecal soiling), are more common in children and young people with ASD compared with typically developing peers.</p> <p><b>Rationale:</b> There was a consistent trend observed across studies indicating that gastrointestinal problems were significantly more prevalent in children and young people with ASD than in those without ASD. However, a grade of B was given to reflect the limitations of the evidence. Limitations to study designs introduce biases to determining the prevalence of GI outcomes in individuals with ASD and without ASD, and lead to the wide variations evident in the current review. Major sources of variation between studies which impacted on prevalence estimates include:</p> <ul style="list-style-type: none"> <li>• how the diagnosis of ASD in sample participants was made and confirmed</li> <li>• how the sample and control group members were identified and recruited</li> <li>• how gastrointestinal problems were defined</li> <li>• how gastrointestinal problems were assessed.</li> </ul>	B
<p><b>4.1.4b</b> Children and young people with ASD should have a full evaluation that includes a thorough assessment of gastrointestinal function. Some children, particularly those with social communication difficulties, may have atypical presentations such as increased anxiety, irritability, disordered sleep patterns, and unusual vocalisations and movements.</p> <p><b>Rationale:</b> A thorough assessment of GI function would often consist of a dietary history, history of bowel function, relevant family history, physical examination of the abdomen, and, where indicated by symptoms or signs of disorder, further investigations or specialist consultation. This evidence is based on consensus expert opinion and cross-sectional studies. Recognition and evaluation of gastrointestinal problems in children and young people with ASD can be more challenging due to the communication difficulties characteristic of ASD.</p>	C

## 10.5 Summary of Supplementary paper on the implications of the DSM-5 for the guideline

The full Supplementary Paper, describing the Living Guideline Group's (LGG) modified and newly developed recommendations and good practice points, and the supportive systematic review, is available from the Ministry of Health website.<sup>16</sup>

### Preamble

This review describes the changes to diagnostic criteria for Autism Spectrum Disorder (ASD) published in the latest version of the Diagnostic and Statistical Manual of Mental Disorders – Version 5, the DSM-5<sup>18</sup> and their rationale, critically summarises relevant empirical research, and outlines key clinical, social and research issues potentially impacted by the application of these changes. The primary goal was not to judge whether or not the diagnostic changes were necessarily a good idea, but to focus on whether and how the the first edition of the New Zealand ASD Guideline needed to change to reflect them.

### The Living Guideline Group process

The Living Guideline Group considered a review of evidence<sup>16</sup> relating to changes in the diagnostic criteria for ASD published in the DSM-5,<sup>18</sup> and the implications for the guideline.

### Key changes in DSM-5

Key changes in the diagnostic classification of ASD in the DSM-5 include:

- The previous version of the manual distinguished conditions as separate subtypes including autistic disorder, Asperger's disorder (Asperger syndrome), and pervasive developmental disorder not otherwise specified (PDD-NOS). However the new version (DSM-5) subsumes these conditions under a single diagnosis of autism spectrum disorder (ASD) with the subtypes no longer specified.
- Criteria previously organised into three symptom domains are now presented under two domains:
  - (1) social communication and social interaction
  - (2) restricted, repetitive patterns of behaviour, interests, or activities.
- The number of symptoms within the domains has been streamlined from 12 to 7. For a diagnosis of ASD, all 3 criteria on the social-communication domain must be present and 2 of 4 criteria in the restricted interests domain must be met.
- Notably, behaviours do not have to be currently present; they may be present only in history (eg, observed in childhood).
- Sensory behaviours (hypo- and hyper-reactivity to sensory input or unusual interest in sensory aspects of the environment), absent from DSM-IV<sup>21</sup> criteria for ASD, are now included under the restricted, repetitive patterns of behaviours domain.



- Dimensional elements have been introduced to reflect how much a condition affects an individual (its “severity” level) in terms of broadly indicating how much support a person needs and in what areas of function.
- Clinical “specifiers” have been introduced to help describe accompanying difficulties and need for supports, including their intellectual ability, language impairment, and co-occurring medical conditions. Delays in language will affect an individual’s clinical presentation but is not a defining diagnostic autism spectrum criterion.
- The requirement that symptoms be evident before the age of 36 months has been removed and replaced with a more open definition of “present in the early developmental period”.
- A new ASD criterion requires that the constellation of symptoms together must “cause clinically significant impairment in social, occupational, or other important areas of current functioning”.
- Another new ASD criterion requires that these disturbances are not explained by alternative diagnoses of intellectual disability or global developmental delay.
- Diagnosis of comorbidities including attention-deficit/hyperactivity disorder (ADHD), stereotyped movement disorder and psychiatric conditions such as anxiety states and schizophrenia are now permitted with ASD.
- A new condition called “social communication (pragmatic) disorder” (SCD) has been included. This applies where someone exhibits the social communication and interaction aspects of an ASD diagnosis, but does not show restricted, repetitive patterns of behaviour, interests or activities.
- The DSM-5 advises that people who already have a definitive diagnosis of Autistic disorder, Asperger’s disorder (Asperger syndrome) or PDD-NOS will (continue to) retain a diagnosis of ASD .

### Response to the DSM-5 changes

The Living Guideline Group echoes the UK’s National Autistic Society (NAS)<sup>447</sup> in finding the DSM-5 revised diagnostic criteria helpful, being clearer and simpler than the previous DSM-IV criteria, and in welcoming the development of dimensional measures of severity, the inclusion of sensory behaviours, and the emphasis on identifying the full range of difficulties that an individual may experience as well as other relevant factors. The LGG also observe that whilst Asperger syndrome may no longer be a distinct diagnostic entity diagnosed under the DSM-5, the concept retains clinical utility in terms of family understanding, self-identity, and as a tool for guiding educational and behavioural interventions and informing services and supports.

The Living Guideline Group recognise that people who identify closely with the term Asperger syndrome may continue to use it in everyday language. And so, regardless of the changes to the classification of ASD in what is fundamentally a diagnosticians’ clinical manual, individuals may choose to self-refer using their own terms of belonging to a culture that transcends psychiatric diagnosis.

The first edition of the guideline was prescient in recognising the movement toward considering autism as a spectrum condition and in the guideline's title and frequently throughout the text and recommendations, the umbrella term of Autism Spectrum Disorder has been used. Nevertheless, when the original guideline was written the DSM-IV-TR manual was current and the terms Asperger syndrome and PDD-NOS were used in research. The Living Guideline Group advise that, in view of the DSM-5, where these terms are used in the guideline they should be read as referring to ASD.

### Revision of guideline recommendations

Good Practice Points	Grade
<p><b>1.3.5</b> Diagnosis of ASD in itself may be sufficient. Attempts to delineate ASD from Asperger syndrome may not be valid and are not necessary.</p> <p><i>Deleted.</i></p> <p><b>Rationale:</b> This Good Practice Point was removed as considered redundant in view of DSM-5 criteria where DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of autism spectrum disorder.</p>	✓

Revised recommendations	Grade
<p><b>1.2.6</b> Test users should ensure that they are aware of the validity, reliability and appropriateness of tests when assessing people with ASD and take these limitations into account when forming opinions and reporting results</p> <p><i>Unchanged.</i></p> <p><b>Rationale:</b> Some diagnostic tools in use are based on DSM-IV<sup>21</sup> criteria, however tools based on DSM-5 are currently in development. It remains the case that the reliability, validity and appropriateness of assessment tools need to be considered when assessing ASD.</p>	C
<p><b>1.2.5</b> Standardised autism, Asperger syndrome and ASD assessment interviews and schedules should be used.</p> <p><i>Changed to:</i></p> <p><b>1.2.5</b> Standardised ASD assessment interviews and schedules should be used.</p> <p><b>Rationale:</b> Words “autism, Asperger syndrome and” removed. Under DSM-5, DSM-IV<sup>21</sup> specified subtypes including autism and Asperger syndrome are subsumed under the one condition of ASD.</p>	B

Revised recommendations	Grade
<p><b>1.2.7</b> The assessment of intellectual, adaptive and cognitive skills associated with autism, Asperger syndrome and ASD should be seriously considered and, where possible and appropriate, formally assessed.</p> <p><i>Changed to:</i></p> <p><b>1.2.7</b> The intellectual, adaptive and cognitive skills associated with ASD should be seriously considered and, where possible and appropriate, formally assessed.</p> <p><b>Rationale:</b> The words “assessment of” were removed as redundant in the sentence structure. Words “autism, Asperger syndrome and” removed. Under DSM-5, DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of ASD.</p>	<p>B</p> <p>B</p>
<p><b>6.2</b> 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.</p> <p><i>Changed to:</i></p> <p>Professionals administering standardised ASD assessment tools should be provided with appropriate training. When reporting the results of ASD-specific tests, caution should be exercised as New Zealand norms have not yet been established.</p> <p><b>Rationale:</b> Wording of the first sentence was altered to improve readability and to recognise that not only “local health care professionals” may administer assessment tools. Words “autism, Asperger syndrome and” removed. Under DSM-5, DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of autism spectrum disorder.</p>	<p>C</p> <p>C</p>
<p><b>6.3</b> Norms should be developed for autism, Asperger syndrome and ASD assessment tools specifically for the New Zealand population</p> <p><i>Changed to:</i></p> <p><b>6.3</b> Norms should be developed for ASD assessment tools specifically for the New Zealand population.</p> <p><b>Rationale:</b> Words “autism, Asperger syndrome and” removed. Under DSM-5, DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of ASD.</p>	<p>C</p>

New Good Practice Points	Grade
<p><b>1.2.14</b> Assessment should consider the influence of diversity such as sense of self, ethnicity, culture, gender, sexuality, religion, socio-economic status, and geographic factors.</p> <p><b>Rationale:</b> Good practice point was proposed to reflect evidence in the review relating to how cultural, social, demographic and economic factors have been shown to influence access to and process of diagnostic classification under DSM-IV.<sup>21</sup></p>	<p>✓</p>

New Good Practice Points	Grade
<p><b>1.2.15</b> Assessment of an individual should elicit and consider whether that person requires, would value, and would benefit from a diagnosis of ASD.</p> <p><b>Additional text:</b> In addition, the LGG wanted it recognised that decisions about assessment should consider whether a person wants or sees the need for a clinical diagnosis.</p>	✓

## 10.6 Summary of Supplementary paper on social skills groups for young people and adults

The full Supplementary Paper, describing the Living Guideline Group's (LGG) modified and newly developed recommendations and good practice points, and the supportive systematic review, is available from the Ministry of Health website.<sup>17</sup>

### Preamble

Social skills groups refer to interventions which provide structured sessions in social skills training in small groups of people of a similar age group and with similar social problems. A session typically includes teaching a specific skill, demonstration of the skill through role playing, practice of the skill, and individualised feedback. Groups meet on a regular basis, typically for 1–2 hours, for several weeks, facilitated by at least one trained instructor/therapist. Parents are typically provided training in concurrent sessions to encourage their children to practice newly learned skills at home.

In considering the evidence identified and synthesised in the systematic review update, the LGG acknowledge the challenges and limitations of evaluating behavioural interventions. In particular, the LGG are aware that lack of consistency within and between outcomes measured across different studies does not necessarily reflect a flawed evidence base. Rather, the variability reflects the complex, dynamic and multidimensional nature of social competence indicators and the richness of the research data.

It should be noted that social skills groups are distinguished from peer mediated strategies in the guideline (endorsed in Recommendation 3.2.2.4) with respect to the source of instruction. Peer mediated approaches are based around interactions with trained, typically developing peers whereas social skills groups involve instruction from adult instructors/therapists.

### The Living Guideline Group process

The Living Guideline Group considered a systematic review of evidence relating to social skills groups in children and young people (6–21 years) with ASD<sup>15</sup> which updated evidence from the NZ ASD Guideline on this topic. Eligible studies were randomised controlled trials of group-based social skills training; that is, a series of group-based training sessions which focus on developing social skills for young people with ASD. Comparison groups were wait list controls, or those receiving usual care and/or no treatment. Eligible outcomes included social competence, social communication, emotion recognition, quality of social interaction/play, problem behaviour, and observed specific behaviours; quality of life (including anxiety and depression); and programme knowledge.

Eligible designs were randomised controlled trials (RCTs) which compare (at least 10) children and young people with ASD randomised to receive a social skills group intervention with those randomised to wait list control, usual care or no intervention. The appraised body of evidence consisted of 12 studies, including two systematic reviews, and 10 RCTs.

### Revised recommendations

Revised recommendations	Grade
<p><b>4.2.1</b> The development of social skills and community support groups for young people and adults should be undertaken to minimise and avoid problems.</p> <p><i>Unchanged.</i></p> <p><b>Rationale:</b> This Recommendation was unchanged. It is broader in scope than the current research which focused on structured and facilitated social skills groups.</p>	C

### New recommendations and Good Practice Points

New recommendations and Good Practice Points	Grade
<p><b>4.2.1a</b> Facilitated and structured social skills groups should be considered for high functioning children and young people with ASD.</p> <p><b>Additional text:</b> Social skills groups as referred to in this new recommendation are defined as interventions which provide structured sessions in social skills training in small groups of people of a similar age group and with similar social problems. A session typically includes teaching a specific skill, demonstration of the skill through role playing, practice of the skill, and individualised feedback. Groups meet on a regular basis, typically for 1-2 hours, for several weeks, facilitated by at least one trained instructor/therapist. Parents are typically provided training in concurrent sessions.</p> <p>Whilst it is acknowledged that the term “high functioning” is not universally favoured in the context of autism, in this recommendation the term “high functioning” is used to refer to people with higher cognitive functioning either as established by intelligence tests (generally indicated by full IQ scores of 70 or above), or through the diagnosis of “high-functioning autism” or Asperger syndrome (under DSM-IV criteria).</p> <p>There is insufficient evidence relating to people who are not verbally fluent, people who use augmentative and alternative communication (AAC), people with intellectual disability, adults, and pre-schoolers.</p> <p>It is not currently possible to offer clear conclusions about the necessary content, approach and intensity of social skills groups. Further research is needed, particularly considering social skills interventions conducted and evaluated in naturalistic settings, and into the generalisation and maintenance of acquired social competence and other salient outcomes.</p> <p>There is insufficient evidence relating to the relative benefits of social skills groups versus other group-based interventions, or individual social skills interventions.</p>	B

New recommendations and Good Practice Points	Grade
<p><b>Rationale:</b> Whilst there is overall evidence of benefit from participating in social skills groups, the recommendation is graded B to reflect the variability in programme content, approach and intensity, large range of outcome variables and measures, and uncertainty about the applicability and generalisability to the New Zealand context.</p> <p>Participants in the included studies were required to demonstrate a level of cognitive and/or verbal ability above a stated threshold as determined from standardised IQ tests (generally indicated by full IQ scores of 70 or above).</p>	
<p><b>4.2.1b</b> Social skills groups approaches in New Zealand need to be responsive to the cultural and linguistic diversity of the group participants.</p> <p><b>Rationale:</b> Further research is needed to explore the applicability and effectiveness of social skills groups in the New Zealand context.</p>	✓
<p><b>4.2.1c</b> Decisions about participating in social skills groups should be guided by whether a person with ASD values it, and whether they are expected to benefit from it.</p> <p><b>Rationale:</b> Interest in participating in a social skills group was a common inclusion criteria for participants in the research trials appraised. Other factors such as the ability to attend, and the ability to participate in the group, may also be considered by the person with ASD, their family, and the programme instructors, in deciding whether a social skills group is suitable.</p> <p>It is noted that the new Recommendation (4.2.1a) and Good Practice Points (4.2.1b and 4.2.1c) could equally sit in Chapter 3, Section 3.2 of the NZ ASD Guideline, after Recommendation 3.2.2.4.</p>	✓

## 10.7 Summary of Supplementary paper on cognitive behaviour therapy for adults

The full Supplementary Paper, describing the Living Guideline Group's (LGG) modified and newly developed recommendations and good practice points, and the supportive systematic review, is available from the Ministry of Health website.<sup>18</sup>

### Preamble

Cognitive behaviour therapy (CBT), also known as cognitive behavioural therapy, is a structured, goal-directed form of psychotherapy directed toward solving current problems by modifying unrealistic and unhelpful thinking and behaviour. CBT aims to help individuals notice and understand the relationship between their thoughts, behaviours and emotions and to develop more helpful ways of thinking about, coping with, and responding to challenging situations. CBT techniques include questioning and testing assumptions or habits of thought that might be unhelpful and unrealistic, gradually facing activities which may have been avoided, and trying out new ways of behaving and reacting. Relaxation and distraction techniques are also commonly included.

In addition to traditional cognitive and behavioural techniques, so-called “third wave CBT” approaches incorporate mindfulness, meditation, metacognitive therapy, compassion focused therapy, and “acceptance and commitment” therapies. These place less focus on addressing unhelpful cognitions, and more on teaching people to accept phenomena (bodily sensations, thoughts, feelings, sounds) as they appear, to counter avoidance strategies, and reduce anxiety.

Cognitive behaviour therapy tends to be short-term and time-limited (often fewer than 16 sessions). Whilst traditionally CBT has been delivered individually on a one-to-one basis, it is also being delivered in group-based formats, and through guided self-help using web-based resources.

### The living Guideline Group process

The Living Guideline Group considered a systematic review of evidence relating to the effectiveness of cognitive behaviour therapy (CBT) for improving social interaction, communication, emotional and mental health outcomes of adults (aged 18 years and over) with autism spectrum disorder<sup>18</sup> which updated evidence from the NZ ASD Guideline on this topic. The review also aimed to describe recommended adaptations to CBT that have been employed with adults on the autism spectrum.

Eligible designs were randomised controlled trials (RCTs), pseudo-experimental designs, single case experimental designs, case series, and case studies, where they reported at least one pre- and post-treatment relevant outcome measure. Primary outcomes included self-report, informant-report and/or clinician/assessor-reported measures of any outcome relevant to social interaction, communication skills, emotional and mental health, general well-being, adjustment and quality of life.

The appraised body of evidence consisted of 13 studies, including three recently published systematic reviews, three randomised controlled trials, two pseudo-randomised and one non-randomised experimental studies, and four small-sampled observational studies.

### Revised recommendations

Revised recommendations	Grade
<p><b>4.3.9</b> Cognitive behaviour therapy should be considered as a suitable treatment for many behavioural, emotional and mental health difficulties.</p> <p><i>Unchanged.</i></p> <p><b>Rationale:</b> Recommendation 4.3.9 related to evidence for people with ASD of all ages. As the effectiveness of CBT for children and young people was out of scope and therefore excluded from the current review update, the Recommendation was left unchanged. To incorporate the updated evidence, a new Recommendation 4.3.9a was developed relating specifically to adults.</p>	C
<p><b>4.3.10</b> Cognitive behaviour therapists should adapt their techniques to take into account the characteristics of people with ASD.</p> <p><i>Unchanged.</i></p>	C

## New recommendations and Good Practice Points

New recommendations and Good Practice Points	Grade
<p><b>4.3.9a</b> Broadly defined cognitive behaviour therapy, adapted for ASD, may assist adults with mental health conditions.</p> <p><b>Additional text:</b> CBT is broadly defined as incorporating traditional cognitive and behavioural techniques in addition to so-called “third wave CBT” approaches which incorporate mindfulness, meditation, metacognitive therapy, compassion focused therapy, and “acceptance and commitment” (ACT) therapies. These place less focus on addressing unhelpful cognitions, and more on teaching people to accept phenomena (bodily sensations, thoughts, feelings, sounds) as they appear, to counter avoidance strategies, and reduce anxiety.</p> <p>It should be noted that the evidence base considered in developing this recommendation related to adults with ASD who do not have an intellectual disability.</p> <p><b>Rationale:</b> The LGG expressed some concern about the term “suitable” in the original Recommendation 4.3.9 as they considered that CBT that has not been modified for people on the autism spectrum may be unsuitable. Therefore the recommendation included a specification that CBT be adapted for ASD. It was challenging to grade this new recommendation given the inconsistency of response of CBT, and the methodological limitations of the research.</p>	C
<p><b>4.3.9b</b> Cognitive behaviour therapy (CBT) has been designed and evaluated predominantly for people without ASD. More research is recommended to further develop and evaluate effective cognitive behaviour therapies and their necessary adaptations for people on the spectrum as well as appropriate and valid outcome measures for research in this field. As it seems likely that some individuals receiving CBT benefit and some do not, future research should also investigate what personal characteristics and aspects of therapy best predict treatment effectiveness.</p> <p><b>Additional text:</b> The heterogeneity and complexity of the current evidence base makes it difficult to draw general conclusions about cognitive behaviour therapy’s (CBT) effectiveness. The findings for similar outcomes varied across as well as within studies. There was wide variability in the evidence with respect to programme content, components and intensity; whether the therapy was delivered in groups or individually; the outcomes measures employed for assessing similar outcomes; and whether there were control groups, and if these were offered active interventions including cognitive behavioural components themselves. It was not possible to qualitatively discern a pattern as to what are the mediators and moderators of treatment effectiveness with respect to these factors.</p>	✓



New recommendations and Good Practice Points	Grade
<p><b>4.3.10a</b> The following adaptations to cognitive behaviour therapy are recommended:</p> <ul style="list-style-type: none"> <li>• <b>Use a structured approach</b> and minimise anxiety about the therapeutic process by being <b>explicit</b> about roles, times, goals and techniques.</li> <li>• Extend the <b>number of sessions</b> and <b>time provided</b> to conduct tasks to accommodate slower information-processing and the mental demands of the therapeutic process. Be <b>flexible</b> about the length of each session and offer breaks to allow for cognitive and motivational deficits.</li> <li>• Provide <b>psycho-education</b> about autism, emotions, and mental health challenges relevant to the client.</li> <li>• Concentrate on <b>well defined</b> and <b>specific difficulties</b> as the starting point for intervention, with less emphasis on changing client's cognitions.</li> <li>• Be more <b>active</b> and <b>directive</b> in therapy, where appropriate, including giving suggestions, information, and immediate and specific feedback on performance. Examine the rationale and evidence for inaccurate, automatic thoughts and collaboratively develop alternative interpretations, concrete strategies and courses of action.</li> <li>• Teach <b>explicit rules</b> and their appropriate context, including the use of verbal, nonverbal and paralinguistic cues to a social situation.</li> <li>• Incorporate specific <b>behavioural techniques</b> where appropriate, such as relaxation strategies, meditation, mindfulness, thought stopping or systematic desensitisation.</li> <li>• <b>Communicate visually</b> (eg, using worksheets, images, diagrams, 'tool boxes', comic strip conversations, video-taped vignettes, peer-modelling, and working together on a computer).</li> <li>• <b>Avoid ambiguity</b> through minimising the use of colloquialisms, abstract concepts and metaphor. Use specific and concrete analogies relatable to the client's concerns.</li> <li>• Incorporate <b>participants' interests</b> in terms of content and modes of content delivery to enhance engagement.</li> <li>• Involve a <b>support person</b>, such as a family member, partner, carer or key worker (if the person with autism agrees) as a co-therapist to improve generalisation of skills learned within sessions.</li> </ul>	✓