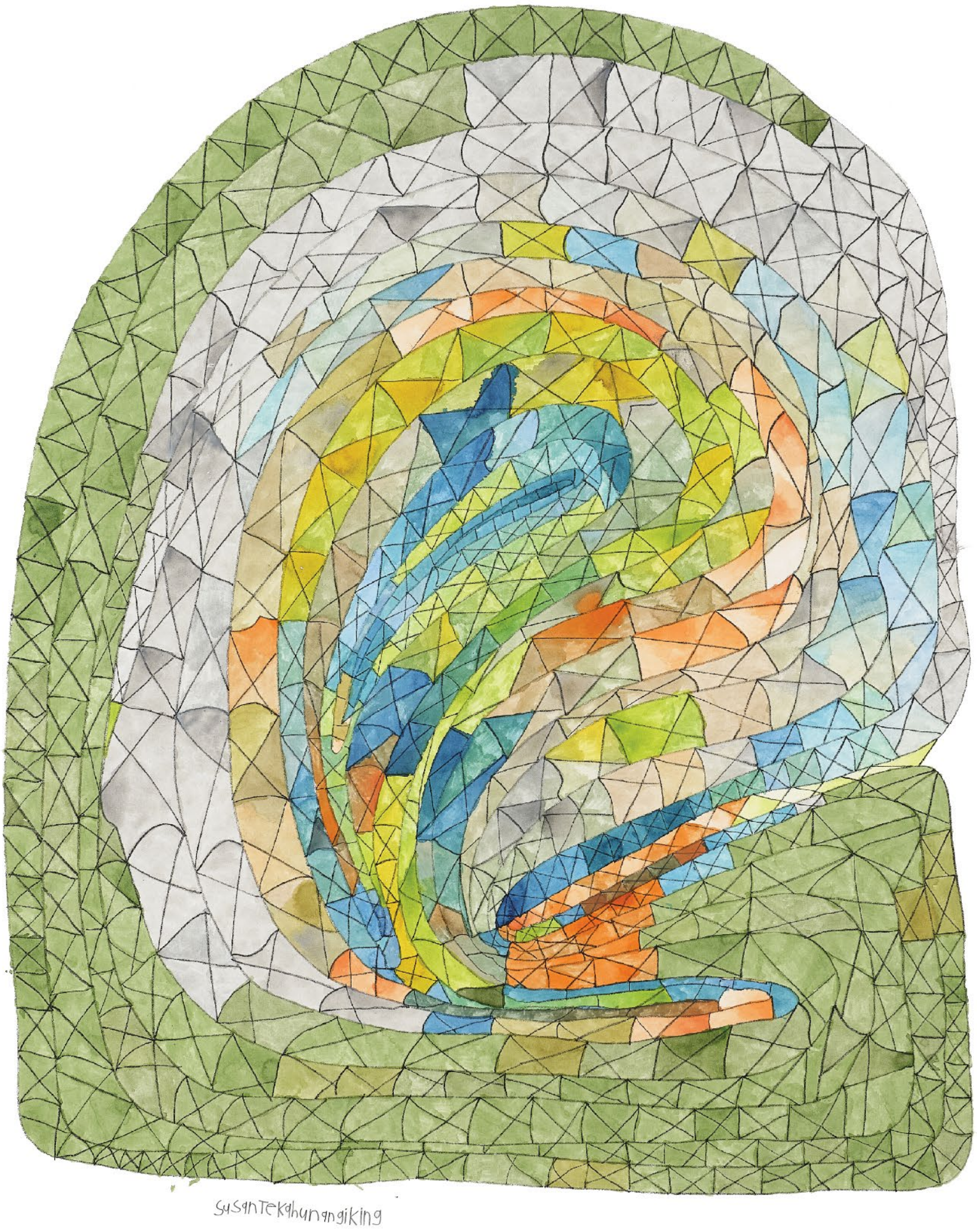

Whaikaha
Ministry of
Disabled People

Aotearoa New Zealand
Autism Guideline:
He Waka Huia Takiwātanga Rau

Third Edition

Source: APS Editions (photographed by Samuel Hartnett)

Cover artwork by Susan Te Kahurangi King

Untitled 11, 2022, edition of six hand-coloured lithographs, 1093 x 775 mm.

About the Artist

Susan Te Kahurangi King, born 1951 in Te Aroha, has been creating extraordinary drawings prolifically and skilfully since her childhood.

She lost her speech around the age of five and cannot read or write. In the absence of being able to communicate directly with others, she expresses her thoughts, feelings, understandings, observations, fears and fascinations through her wonderfully varied and unique drawings.

In the early 1990s, Susan's practice of drawing came to a complete stop. Fifteen years passed until 2008, when much to the family's surprise and Susan's own delight, she picked up a pen and returned to her long-lost love of drawing. Since then, her oeuvre has broadened, including her recent collaboration with APS Editions, drawing directly on lithographic stones and hand-colouring the resulting limited edition prints (as shown in the cover art).

King has featured in many exhibitions, events, and publications as both an 'Outsider Artist' and a 'Contemporary Artist'. She has works in significant collections including the Museum Of Modern Art (MoMA), The Philadelphia Museum of Art, and the Chartwell Collection (Auckland Art Gallery Toi o Tamaki).

Although Susan attended a special school for people with disabilities between 1960 and the late 1980s, it wasn't until 2015, at the age of 64, that she was assessed and diagnosed with autism.

Susan Te Kahurangi King currently lives in Hamilton and continues her practice as a contemporary artist, relishing her emersion from half a century of producing work in obscurity.

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Kupu whakamārama mō te ingoa

A word of explanation about the title

He Waka Huia Takiwātanga Rau

A vessel for housing our many precious taonga

Waka huia	treasure container for our most precious *taonga*
Takiwātanga	autism
Rau	many
Rau huia	precious huia plume (a reference to our autistic whānau).

Acknowledgement: Morehu Nikora and Dorothy Taare-Smith

Whakapūpūtia mai ō mānuka kia kore ai e whati

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

This edition of the 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

Autistic people/tāngata whaitakiwātanga and their families/whānau

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

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

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

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

> “It is not wrong to think in a different way.”[5]

> “I am tired of having to do 100% of the changing, and there is no change with most people without autism.”[6]

“I feel close to my mum, stepfather, and sister, and sometimes I do things with them … Most of the time, I prefer to be alone to pursue my interests.”[7]

“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.”[6]

“My mum came to school at the beginning of each year and talked to both the students and the teachers about autism and me. I think that helped everyone understand me better. I especially liked it when she talked about all the things I am good at.”[7]

“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."[7]

"I am sick of social skills groups ... Why can't someone go to the bar with me or to chess club?"[8]

"Parents become highly educated – of necessity, not of choice."[9]

"Getting diagnosed by a professional, familiar with the depth and breadth of autism, as an adult was the start of my journey towards self-acceptance. I wish there had been more follow-up afterwards though I was fortunate to find, and be supported by, other Autistic adults".[10]

"Many autistic adults 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."[6]

"Getting a diagnosis as an adult was both a cause for celebration and sadness. Celebration, because now I could understand myself so much better and sadness because as a teacher I could see the potential in the autistic students that were so similar to me at that age, but their teachers, my colleagues often did not."[11]

"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."[8]

"I see my diagnosis of autism as positive because I can support my autistic sister and my autistic friends who had been told by their parents that autism was brain damage and a negative thing. It's also liberating as now I look at how things affect me and that my sensory things are not negative, they are just autism. I wish my teachers knew more about autism and how to teach autistics effectively".[12]

"Because we didn't know anything about autism when our daughter was really young we thought her moods were really erratic and the public hospital wanted to test her for a 'violent gene'. But getting her diagnosed by a specialist as autistic we were supported by the diagnostician to focus on identifying and then minimising her triggers so her moods significantly stabilised and the violence disappeared. The list of possible triggers provided to us was invaluable. The whānau has helped her to see difference as ok and the diagnostician presented it in a way that enabled us to see autism as a positive part of life. The teachers assumed our daughter was intellectually disabled because she didn't talk at school, but we knew she talked at home".[13]

"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."[5]

Contents

Overview

“Ko te ahurei o te tangata
arahi ō tātou māhi”

Let the uniqueness of the
person guide our work

Overview

Purpose of the Aotearoa New Zealand Autism Guideline

This Guideline is intended to provide guidance around supporting autistic people in Aotearoa New Zealand across the lifespan. The Guideline is an evidence-based summary that covers the identification and diagnosis of autism spectrum disorder (ASD), and ongoing assessment and access to supports and services for autistic individuals. It seeks to provide the best evidence currently available to assist informed decision-making to improve the health, educational and social outcomes, and lives of autistic individuals. The Guideline is intended for use by primary care practitioners, education professionals, service providers, policymakers, funders, specialists, carers, and autistic people/tāngata whaitakiwātanga and their families and whānau.

Disclaimer

Evidence-based practice guidelines are produced to assist health professionals, educators, service providers, and individuals make decisions about education and optimum support in specific 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 approach 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 for meeting each individual's support needs.

About the Aotearoa New Zealand Autism Guideline

Foreword

We are pleased to release of the third edition of the Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau.

Every person has the right to live in an inclusive community where they can access education, health and other services in ways that support their sense of belonging. This will help them to live their lives fully and meaningfully. This evidence-based practice Guideline supports that kaupapa. It is the world's first "living guideline" in this area. It is regularly updated to remain responsive to the needs of autistic people in this rapidly evolving field.

The Guideline provides an opportunity to better understand and communicate best practices for supporting people on the autism spectrum and their families and whānau. It also provides a framework for improving services, based on robust and reliable information.

People diagnosed with autism (takiwātanga) in Aotearoa New Zealand are able to access disability support services. When Whaikaha – Ministry of Disabled People was established in July 2022, the responsibility for delivering and transforming disability support in line with the Enabling Good Lives approach transferred to Whaikaha from the Ministry of Health.

Historically the Guideline was co-funded by the Ministries of Health and Education. This latest edition is proudly led by Whaikaha – Ministry of Disabled People in partnership with the Ministry of Education.

A key intent of Whaikaha is that it gives full effect to the individual and collective voices of disabled people, tāngata whaikaha Māori and their whānau, so it is appropriate to see the voices of those on the autism spectrum reflected in the Guideline.

This Living Guideline is a world-leading collaborative effort of researchers, clinicians, educators, community service providers, and government agencies. Crucially, it has been informed by the perspectives and language preferences of autistic people, te ao Māori experts, and Pacific Peoples experts.

We recognise the dedication of all these contributors to provide this comprehensive best practice Guideline. It affirms the Government's commitment to having meaningful, current, evidence-based resources to support autistic people and their families and whānau.

Hon Poto Williams Minister for Disability Issues	**Hon Jan Tinetti** Associate Minister of Education

Preface to the third edition

I was an educator completing my PhD in Christchurch at the University of Canterbury when I received my autism diagnosis. I had been researching interactions between teachers and their autistic students. Having supported the education of autistic children and young people for most of my teaching career, I wanted to know why I enjoyed teaching autistic students and understood them, but some of my colleagues did not.

I sought out an autism assessment because, for the first time, I was supporting and researching girls with an autism diagnosis. To my mind, these girls were ‘mini-me’, which created an unfathomable contradiction in my thinking. I had a successful career, had a long-term relationship and was parenting a young person reasonably well. And yet, these girls, who were presenting in ways that were so familiar to my lived experience, were being seen by parents, educators and other professionals as having very high support needs and being unlikely to live independently in the future. This was despite being able to express themselves verbally and being able to read and write when starting school.

If I had been born now, I would have been diagnosed as autistic as a child. I presented with behaviours that are now understood to be characteristics of autism. I would not eat if there was more than one of each food on my plate, and I still struggle to eat foods that are touching each other when they shouldn’t be. I was hyperlexic (able to read at a level far above my age) with an impressive memory, memorising whole scripts to act as the prompter for my parent’s theatre group. All things that when I was doing my post-graduate studies in special education, I learnt were pathologised in autistic individuals.

The first edition of these Guidelines was a ray of hope that autism/takiwātanga and autistic people/tāngata whaitakiwātanga would one day be accepted for who we are, complete with our unusual gifts and range of surprising support needs. I had a hard copy of the Guidelines on my PhD research shelf with so many bookmarks that yellow paper burst from the top and doubled the width of the book!

Some of my unusual gifts are an excellent auditory memory, the ability to feel distress in anyone around me and a passion for taking photographs of visual textures. Surprising support needs, in many people’s eyes, are my inability to tell left from right, open door locks and appalling proprioception, which is the sense of your body in space (meaning I bump into things and open doors into myself all the time). I also struggle with social communication despite being a skilled and experienced public speaker.

Reading this latest edition of the Living Guideline, I am excited by the inclusion of autistic lived experience voices from across Aotearoa including the voices of tangata whenua and Pacific Peoples. In conjunction with the clearly explained research evidence and recommendations/good practice points, these voices highlight the potential of autistic people/tāngata whaitakiwātanga. It is my hope that as autistic New Zealanders can access timely assessment processes and receive their diagnoses in a positive manner, their journey will be guided by parents, whānau and professionals seeking to minimise distress and maximise potential.

Neurodiversity has been embraced in the text in a way that does not diminish the support needs of autistic people/tāngata whaitakiwātanga, but does make it clear that the aim should be to support us to be the best autistic person that we can be, and not to try and make us non-autistic.

I am honoured to have been involved in this edition and to work with people who are so passionate about improving the outcomes for all autistic people/tāngata whaitakiwātanga across the lifespan. My hope is that readers action both the recommendations/good practice points and the sentiments behind this edition as this is what will enable the greatest quality of life for autistic individuals.

Emma Goodall

Autism Guideline development process

Background to the first edition

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 several recommendations to improve the quality of autism-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 (now Oranga Tamariki) were represented in this group. ASIWG was set up to implement the recommendations of the review and agreed to oversee the development of an Aotearoa New Zealand autism guideline (henceforth, 'the 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 a Guideline. For the first time in Aotearoa New Zealand, an autism 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 autistic people/tāngata whaitakiwātanga, 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 autism initiatives and to oversee the completion of the 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 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 autistic adults; parents/families of autistic people/tāngata whaitakiwātanga; 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 (now Oranga Tamariki); Pacific advisors; school principals; early intervention services; the Ministry of Education, Learning Support (previously. Special Education); 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 Guideline. Primarily, this involved funding the work of the three workstreams set up to develop the 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, Learning Support (previously. Special Education) 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 for the project.

Structure of the Guideline

The Guideline is divided into eight parts. Part 1 covers the identification and initial assessment of children, young people and adults on the autism spectrum. Part 2 focuses on how best to provide support to people who share their lives with autistic individuals. It also outlines the personal health needs of autistic people/tāngata whaitakiwātanga. Part 3 covers educational principles and approaches for children and young people growing up on the autism spectrum and guidance for education sector organisation and management. Part 4 covers a range of supportive approaches for mental health and wellbeing for autistic people and provides evidence-based guidance on how difficulties can be prevented, minimised, or alleviated. Part 5 focuses on the support needs of autistic people/tāngata whaitakiwātanga 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 autistic people/tāngata whaitakiwātanga, from awareness raising to highly specialised training. Parts 7 and 8 cover the perspectives and experiences of Māori and Pacific people on the autism spectrum and explore issues of information needs, diagnosis, assessment, support, access, services and support decisions for these populations.

Process of development

The Guideline was originally written in separate sections by three workstreams and experienced Māori and Pacific researchers. The three workstreams, each with particular expertise, were set up to represent different aspects of autism/takiwātanga and the different contexts in which autistic people/tāngata whaitakiwātanga live, learn, work and play.

Workstream 1 was led by the Paediatric Society of New Zealand under contract with 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 supportive approaches, 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 supports and services for tāngata whaitakiwātanga in a culturally appropriate manner.

Separate methodologies were followed by the different contributors to the 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 (NAPC)[14] 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 directed the comprehensive literature searching for this Guideline, and the evidence tables that informed the development of Recommendations, can be requested from Whaikaha – Ministry of Disabled People.

A rigorous systematic review process was also established for the updates conducted through the Living Guideline process, recommendations of which have been incorporated into the second and third editions of the 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, e.g., 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
Good Practice Point:	
Where no evidence is available, best practice recommendations are made based on the experience of the Guideline Development Team/Living Guideline Group or feedback from consultation within New Zealand.	✓

Where a recommendation is based on the lived experience, cultural experience and/or professional expertise of members of the Guideline Development Team or Living Guideline Group, it is referred to as a Good Practice Point (GPP) (*see Appendix 1* for further details on process).

Living Guideline process

The 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 given new evidence.

A small multidisciplinary team form the Living Guideline Group (LGG), an expert advisory panel responsible for identifying topics for update, considering new evidence, and reporting on any implications for Guideline recommendations. Autistic and Māori expertise are represented alongside providers and researchers relating to disability, health, mental health, education and support services. Membership of the LGG (past and present) 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, and new ones are developed.

A comprehensive Supplementary Paper describing the systematic review and LGG decisions is prepared for each updated topic.[15] [16] [17] [18] [19] [20] [21] [22] [23] [24] [25] [26] [27] These are published annually on Whaikaha – Ministry of Disabled People's website: https://whaikaha.govt.nz/about-us/policy-strategies-and-action-plans/NZ-autism-guideline/

Revisions from the first seven updates[15] [16] [17] [18] [19] [20] [21] were incorporated into the second edition of the Guideline, and an additional six updates into this third edition.[22] [23] [24] [25] [26] [27] Summaries of each topic update, the scope of the systematic review, and details of the Living Guideline Group's revisions, rationale and any additional supplementary text, are presented in Appendix 3.

As Autism/Takiwātanga Living Guideline Manager, 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.

Historically the Guideline was co-funded by the New Zealand Ministries of Health and Education. This latest edition and the Living Guideline process is proudly led by Whaikaha - Ministry of Disabled People in partnership with the Ministry of Education.

What's new in the third edition?

This new edition includes 308 Recommendations and Good Practice Points. In addition to incorporating recommendations from the most recent six Living Guideline updates,[22] [23] [24] [25] [26] [27] the new edition provided the opportunity to introduce changes in language and terminology, as illustrated by the new title.

Perspectives of autism have markedly evolved since the Guideline was first published in 2008, led by the autistic community. Shifts in preferred language have been steadily integrated into successive Living Guideline updates. A key change has been the rejection of the word disorder and the acronym ASD to describe autism. This preference is consistent with a consideration of autism as a condition that reflects natural neurological variation in how the brain works (its neurodiversity) rather than pathological impairment.[34] This perspective highlights the strengths of autism whilst acknowledging associated challenges.

In this edition, the acronym ASD is largely avoided except when used to refer to a person's clinical diagnosis, or diagnostic tools or services. Consistent with autism being regarded as part of a person's identity, the terms 'autistic person' and 'person on the autism spectrum' are used instead of 'person with ASD'. Other language changes that attempt to depathologise the discussion of autism include avoiding terms such as 'high functioning', 'low functioning', 'problem behaviour', 'non-verbal' (to describe a person with complex communication needs), 'comorbidity', 'symptoms', 'impairments', 'deficits', 'treatment', and 'management'.

Changes were also introduced to increase the prominence of Māori perspectives. There is greater use of te reo, including the use of 'takiwātanga' for autism, meaning 'in my/their/his/her own time and space' (developed by Keri Opai).[41] Frameworks that reflect te ao Māori are described, including four dimensions of well-being (Te Whare Tapa Whā), and goals and principles to achieve excellent and equitable outcomes for Māori (Ka Hikitia's Outcome Framework).[43] Supporting these with actionable strategies are 11 new Good Practice Points, derived from evidence identified by the original literature review and hui, and a Living Guideline update on ethnicity.[22]

In response to concerns raised since the publication of the Supplementary Paper on Applied Behaviour Analysis (ABA)[15], the LGG prepared an additional commentary for the third edition.

Finally, a significant new recommendation (Key Recommendation 7 in Part 4 of the Executive Summary; Good Practice Point 4.3.13) was developed. It sets out guidance for individuals and whānau in choosing a supportive approach, strategy, practitioner or therapist to ensure principles for ethical practice are followed.

How to read the third edition

The Living Guideline process leads to the development of revised and new recommendations and good practice points for each annual topic update. Revisions for 13 completed update topics have been incorporated into Tables.[15 16 17 18 19 20 21 22 23 24 25 26 27] New recommendations and good practice points (except Key Recommendations) are indicated through the addition of a sub-level to the numbering (e.g., new Recommendation 4.3.5a is inserted after existing Recommendation 4.3.5). A reference is also included in the appropriate section of Appendix 3.

An exception are the 11 new Good Practice Points (GPP) developed for the third edition in Part 7 on Māori Perspectives. These have been numbered 7.6–7.16 to continue from the original numbering. This is to reflect they're being derived from evidence included in the original Guideline, rather than new evidence considered through the Living Guideline process. These additional GPPs aim to give greater prominence to the originally included content on Māori perspectives.

Consultation

To finalise the draft of the first edition of the Guideline, a four-month written consultation process was undertaken. Feedback was sought from across the health, education, disability, and social service sectors.

At the same time, an expert peer review process was undertaken with nine international experts in autism. 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 Guideline. A report on the analysis of 108 submissions received from the open consultation process was provided to all submitters on request.

A focused consultation process was also conducted for each of the annual updates as part of the Living Guideline process. Details are provided within each Supplementary Paper.[15] [16] [17] [18] [19] [20] [21] [22] [23] [24] [25] [26] [27]

Acknowledgements

The third edition of the Guideline is proudly led by Whaikaha - Ministry of Disabled People in partnership with the Ministry of Education. Earlier editions were co-developed and co-funded by the New Zealand governments' Ministries of Health and Education.

In addition to the many people involved in the original Guideline and the Living Guideline process listed in Appendix 2, the following individuals contributed to the third edition.

Autism/Takiwātanga Living Guideline Manager **Marita Broadstock** (INSIGHT Research) revised the third edition and was its technical editor. She consulted with two experts who provided direction and guidance around Māori and Autistic perspectives, respectively.

- **Jill Bevan-Brown,** Associate Professor (retired), educationalist, academic, and author, Jill advised on many significant revisions relating to Māori perspectives. She also developed 11 new Good Practice Points for Part 7 and suggested whakatauki.
- **Emma Goodall**, Autistic author, artist, writer, speaker, and researcher. Emma advised on extensive revisions relating to Autistic perspectives.

Revisions for the third edition were supported by current members of the Living Guideline Group (in alphabetical order):

Tanya Breen, clinical psychologist

Joanne Dacombe, autistic self-advocate (LGG Co-Chair)

Vijaya Dharan, educational psychologist, educator and academic

Elizabeth Doell, speech and language therapist and academic

Matt Eggleston, child psychiatrist (Outgoing LGG chair)

Andrew Marshall, developmental paediatrician (LGG Co-Chair)

Martyn Matthews, autism researcher

Daniel Smith, autistic self-advocate

Dorothy Taare-Smith, Takiwātanga education facilitator and whānau advocate

Larah van der Meer, autism researcher.

Representing the funders were ex-officio LGG members **Helen Hayes** (Whaikaha – Ministry of Disabled People) and **Donna Caddie** (Ministry of Education).

The revisions were also informed by the work led by Autistic advocate and researcher Dr Ruth Monk in developing a guide on preferred language and terminology. This project involved wide consultation with the autistic community and was funded by Autism New Zealand.[28] Joanne Dacombe (Co-Chair LGG, and Chair of ASAN AUNZ Board) provided autistic peer review and proofing, offering helpful insights on many issues. Both were very generous with their time and wisdom.

Morehu Nikora and Dorothy Taare-Smith developed the kupu and kupu

whakamārama for the title. Tofa Suafole Gush (Whaikaha – Ministry of Disabled People) suggested the Niuean proverb for Part 8 (Pacific Peoples' perspectives).

The Ministry of Education Library provided access to databases and publications, and library staff organised interloans.

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Declaration of competing interests

There were no competing interests declared by any contributors.

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Executive summary

Autism is a neurodevelopmental condition that affects an individual's social interactions, behaviour, and overall ability to interact with their environment. It is a permanent condition. It can be accompanied by significant and often serious disability for autistic individuals and challenges for those who care for or educate them.

This Guideline addresses identification, assessment, diagnosis, supports and services for autistic individuals. These topics are covered in separate parts of the Guideline, according to the following structure:

Part 1: Diagnosis and initial assessment

Part 2: Support for individuals, families and carers

Part 3: Education for learners

Part 4: Supportive approaches for mental health and wellbeing

Part 5: Living in the community

Part 6: Professional learning and development

Part 7: Māori perspectives

Part 8: Pacific Peoples' perspectives

The term ASD (Autism Spectrum Disorder) is the diagnostic term used to refer to a condition that affects communication, social interaction and adaptive behaviour functioning. In the DSM-5[29] four pervasive developmental disorder subcategories specified in the diagnostic manual's predecessor, the DSM-IV,[30] 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 (*see* Appendix 4 *for diagnostic criteria*).

The spectrum of autism is now recognised as covering a wide range of support needs and intellectual abilities.

As specified in the DSM-5,[29] individuals 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 that cause clinically significant impacts in social, occupational, or other important areas of current functioning, although their intensity may vary.

Part 1: Diagnosis and initial assessment

Part 1 of this Guideline focuses on the diagnosis and initial assessment of children, young people and adults. The earlier the diagnosis of autism is made, the greater the impact early support has, resulting in fewer 'behaviours of concern' (see discussion of this term under Autistic Perspectives in the Introduction) and better outcomes for families and whānau. The identification of autistic children usually occurs through parents and their general practitioner (GP) or, at a later stage, through a child's teachers. Primary care professionals must monitor developmental milestones at Well Child visits to improve rates of early identification. All health care and education professionals need to be responsive to alerting signals of possible autism and be receptive to parental concerns about their children.

Professional concerns about autistic children with less obvious support needs 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 autism in children in separate age bands: 1 to 3 years and 4 to 8 years.

Diagnosis is also important in young people in their teens and adults, although for some of these people diagnosis may only be of academic interest. Others, however, may suffer undue stress, miss out on effective support options and receive inappropriate medical, psychiatric and educational approaches if diagnosis is missed. Telling a person that they have been diagnosed with autism should be undertaken sensitively, giving the person ample time to ask questions, understand what is being said and express 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 support needs of an autistic person/tangata whaitakiwātanga and their family. This results in an identification of needs and a plan of action to meet these needs.

Autism/takiwātanga is a developmental condition. Its presentation will vary with age and will vary over time and context in any individual. In Aotearoa 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 autism services is recommended for all people seeking an autism assessment. 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 autism/takiwātanga 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 for autism 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 on the autism spectrum is essential. Early identification enables early intervention and is likely to lead to a better quality of life. Early identification is achieved by: a. comprehensive developmental surveillance of all children so that variations from typical development are recognised early b. valuing and addressing parental concerns about their child's development c. prompt access to diagnostic services.	B
2. Te Whatu Ora Health New Zealand should have in place processes that ensure: a. referral pathways for children and adults who may be on the autism spectrum or have developmental challenges are clearly understood by professionals b. services are coordinated within and across sectors c. multidisciplinary, multiagency assessments are provided d. all services are provided in a timely manner.	C
3. All children suspected of being on the autism spectrum or having other developmental challenges should have an audiology assessment.	✓
4. Preferably, a multidisciplinary team of health care practitioners experienced in autism should undertake diagnostic assessment of young people and adults suspected of being autistic. In the absence of an assessment team, a health care practitioner trained and highly experienced in autism may undertake diagnostic assessment.	B
5. Diagnostic assessment of young people and adults should be comprehensive and involve the person concerned in interview and observation.	C
6. Standardised ASD assessment interviews and schedules should be used. The intellectual, adaptive, and cognitive skills associated with autism/takiwātanga should be seriously considered and, where possible and appropriate, formally assessed (*see Appendix 3.5*).	B
7. Health care professionals must have a good understanding of the different forms of expression of autism across developmental stages and the features 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 autistic people/tāngata whaitakiwātanga. It also deals with the health support needs of people on the spectrum.

The needs of people who share their lives with individuals on the autism spectrum are extensive. Autism/takiwātanga 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 an autistic person/tangata whaitakiwātanga. 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 and rural and cultural issues are also discussed. The provision of information on autism/takiwātanga is seen as crucial by parents and families. It should take a variety of forms, be available in different languages and take into consideration differing needs, both geographic and cultural. Effective educational programmes for parents and families lead to improved outcomes both for people on the autism spectrum and their carers, families and whānau.

The health care needs of an autistic person/tangata whaitakiwātanga can be complex and the appropriate care for these needs can be exacerbated by the characteristics of autism itself. Specific health care needs, such as poor dental hygiene, sleep disturbance, gastrointestinal symptoms, sensory issues and unpredictable drug reactions, underscore the importance of a comprehensive medical assessment for people on the autism spectrum. In Aotearoa New Zealand, the health care of autistic children 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 on the spectrum avoid visiting health or related services because of anxiety or fear, previous negative experiences and/or social and communication difficulties. Thus, some autistic people/tāngata whaitakiwātanga need support to manage their physical wellbeing appropriately, and health care professionals require knowledge of autism/takiwātanga and how it affects their clients to be able to provide optimum health care services.

Since autism is a heterogeneous condition with a wide range of presentation of characteristics, age at diagnosis, intellectual ability, communication abilities and preferences, 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.	Autism-related counselling and/or advocacy services and education should be available to all family members and carers.	C
3.	Family members need to know how to find and access information and support. Health authorities and support groups must work together to develop appropriate support services for adults and their partners to ensure sources of support and information are available.	C
4.	A key service to support families and whānau is the provision of information about autism/takiwātanga. 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 on the autism spectrum who require assistance to manage their physical wellbeing and health care.	C
6.	Medical and health care practitioners should take into account the characteristics of autism in their autistic clients/patients and adapt their practices and procedures accordingly.	C
7.	Physical activities provide benefits across social, cognitive, and behavioural domains in addition to general wellbeing and should be considered for children and young people on the autism spectrum.	B
8.	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 autism.	A
9.	Health-promotion campaigns should ensure that autistic people are included as a specific target group.	C
10.	Sensory issues in autistic people should be identified and appropriately assessed by occupational therapists with experience in autism. These assessments should lead to specific recommendations.	B
11.	Methodologically rigorous research is needed to examine the effectiveness of current evaluation methods and approaches used to address sensory issues.	B
12.	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
13.	A coordinated approach to planning and implementing services should be developed to meet the identified needs of an autistic individual, including linkage or integration and coordination of multiple services.	✓

Part 3: Education for learners

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

Most overseas educational programmes are based on three broad models: discrete trial training (DTT), approaches that draw on contemporary 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, learning support practice in Aotearoa New Zealand emphasises participation and development, rather than treatment or 'fixing' the child.

There is good agreement that best practice for learners on the autism spectrum is not achieved by teaching in isolated settings away from other children, and that the quality of the programme 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 several different curriculum areas for children and young people on the autism spectrum in the educational setting and how they influence learning.

It covers:

- communication and literacy skills
- social development
- sensorimotor development
- cognitive development and thinking skills
- self-management skills and addressing 'behaviours of concern'.

For each of these areas, the Guideline assesses the evidence for effective programmes 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 autistic child 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 autism, and understanding and willingness to work in a team with the family/whānau. Transitions for learners on the autism spectrum need to be carefully planned to minimise stress.

Key recommendations for education for learners on the autism spectrum		Grade
1.	Programmes should start early, as soon as significant developmental delay is recognised, and be proactive. The child or young person's programme should be culturally responsive, individualised, 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, i.e., with their usual carers and teachers, and with access to peers who are not autistic.	B
5.	There is no evidence that any single model is effective for teaching every goal to all autistic children. 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 and culture 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.	Programmes 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 programme 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 programmes 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 on the autism spectrum should be carefully planned.	B

Part 4: Supportive approaches for mental health and wellbeing

Part 4 covers support for mental health challenges (affecting behaviour, emotion regulation, and mood) that can be experienced by children, young people and adults on the autism spectrum. Although some of these difficulties can be prevented or minimised by programmes with a totally educational component, other approaches with a different focus may also be helpful for autistic people/tāngata whaitakiwātanga.

People on the autism spectrum have an increased likelihood of developing behavioural and emotional difficulties from childhood. Once 'behaviours of concern' have become established, they are not likely to decrease without supportive approaches and are more likely to worsen than improve. Minimisation and prevention of 'behaviours of concern' early in life are essential. Long-term difficulties may arise if communicative, social, and repetitive tendencies that present difficulties for the autistic child are not attended to.

The first step in support for mental health challenges is a comprehensive assessment that takes into account the family, whānau, and social and cultural context. Components of comprehensive support plans include those that address the environment, educational services, psychosocial approaches, communication, behavioural needs, and the suitability (or not) of medication.

Supportive, educational, and behavioural approaches are the mainstay of support. Autism is not a disease so medication is not a 'cure' for autism/takiwātanga. Environmental strategies should be the first consideration when supporting autistic individuals. However, several medications may be helpful in significantly improving various target areas and associated conditions. There is very limited information on long-term safety, particularly on some of the newer medications and there are additional challenges when the autistic person/tangata whaitakiwātanga has a co-occurring condition. 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 autistic people/tāngata whaitakiwātanga will develop serious dangerous behaviours. Strategies for these situations are discussed. The role of clinical services is also outlined.

Key recommendations for mental health and wellbeing support		Grade
1.	Programmes should encourage functional development, teach skills for independent living, and minimise stress for the person on the autism spectrum, and their family and whānau.	B
2.	Pre-programme assessments should gather detailed information on behavioural, emotional and mental health difficulties, address differential diagnosis, screen for medical conditions and address cultural and environmental issues.	B
3.	Support plans should be comprehensive, and include behavioural needs, educational programmes, psychosocial approaches, communication, environmental, cultural and systems issues and the suitability (or not) of medication.	B
4.	Professionals, autistic people, family, whānau and carers should work together to evaluate approaches before and during implementation.	C
5.	Facilitated and structured social skills groups should be considered for children and young people on the autism spectrum with less obvious support needs (*see Appendix 3.6*).	B
6.	All behavioural approaches should be of good quality and incorporate the following principles: person-centred planning, functional assessment, positive strategies, multifaceted, focus on the environment, meaningful outcomes, focus on ecological validity and systems-level intervention.	C

	Key recommendations for mental health and wellbeing support	Grade
7.	In choosing a supportive approach, strategy, practitioner or therapist, the following principles for ethical practice are recommended: • **Accept the person as authentically autistic**. Respect neurodivergence as difference that does not need to be cured. • **Be strengths-based**. Identify and work with an autistic person's strengths, abilities and potential. • **Be person-centred**. Focus on the needs and autonomy of the autistic person. Consider their culture, needs and choices in identifying an approach and its goals. • **Avoid encouraging masking** of a person's autism/takiwātanga. Do not target reducing behaviours (such as 'stims') which are not harmful or a barrier to desired goals (e.g., do not demand eye contact). • **Understand that behaviour is communication** and where harmful or 'challenging', focus on understanding its purpose and achieving positive change through alternative ways. • **Identify, encourage and facilitate access** to use of supports, modifications, and adjustments (rather than getting the autistic person to do all the changing) • **Presume competence and potential**. Assume an autistic person has the capacity to think, learn, and understand regardless of how they communicate. • **Provide access** to communication modalities that facilitate an autistic person's ability to process and express (e.g., augmentative and alternative communication (AAC) devices, signing, quiet space) • **Do not use** seclusion and restraint, or aversive practices (*see also Recommendation 3.2.5.3*) • **Be collaborative**. Work alongside supportive family, carers, and professional providers, therapists, and educators • **Regularly assess consent**. Look for signs of disinterest, disengagement, or distress and consider reducing intensity, taking a break, or ceasing an approach altogether. • **Monitor progress** regularly (*see also Recommendation 4.3.3*). • **Commit to the dignity, civil liberties and human rights** of people served. Comply with United Nations Convention on the Rights of Persons with Disabilities (2008) and the United Nations Convention on the Rights of Children (1989)	✓
8.	SSRIs (e.g., fluoxetine) may be effective for some children on the autism spectrum with high anxiety and/or obsessive compulsive 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

Key recommendations for mental health and wellbeing support	Grade
9. The antipsychotic medication risperidone is effective in reducing aggressive behaviour, irritability, and self-injurious behaviour in children on the autism spectrum. 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
10. A number of other medications may be helpful in significantly improving various target areas and associated conditions. The choice of medication will be guided by the clinician's assessment of the area to be targeted. Clinicians and interested others should refer to the full discussion of pharmacotherapy in the Guideline.	C
11. When severe behaviours are evident, autistic people need to be assessed for co-occurring conditions such as seizures, attention deficit hyperactivity disorder (ADHD), anxiety disorders, depression, and gastrointestinal problems (*see Appendix 3.4*).	C
12. Music therapy can enhance social communication skills and should be considered for children and young people on the autism spectrum.	B
13. In severe or life-threatening situations, medication may be the optimum therapy.	C
IMPORTANT NOTE FOR PRESCRIBERS: 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.	C

Part 5: Living in the community

Part 5 identifies the support and transition needs of autistic people/tāngata whaitakiwātanga and those who make up their support network as they relate to community living. This is mostly focused on older children, adolescents and adults on the autism spectrum.

Transitioning 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 autistic person/tangata whaitakiwātanga. The transition from secondary school into further and post-compulsory education should be carefully planned, with support needs identified. Providers of further education need to know the specific educational needs of autistic people to maximise the opportunity for educational success.

Autistic young people and adults often experience difficulty securing and maintaining work. The work prospects and experiences of autistic people/tāngata whaitakiwātanga improve if their autistic characteristics (both as strengths and as support needs) and cognitive ability are taken into account. Positive work outcomes (e.g., increased chances of finding work, maintaining work and having good working relationships) for autistic people (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 toward their autistic employees.

For some autistic people/tāngata whaitakiwātanga, 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 in life skills. Common barriers to participation for autistic people 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 on the autism spectrum.

It is commonly believed that autistic people/tāngata whaitakiwātanga and those with 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 autism/takiwātanga with criminal behaviour. Given the nature of autism, young people and adults on the autism spectrum 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 autistic person when having contact with the police, advice for the family and whānau and support persons of young people and adults on the autism spectrum when having contact with the police and courts, and autism-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 autistic people leaving school and moving into further and post-compulsory education, work (paid or unpaid) or vocational services.	C
2.	Services for young people and adults on the autism spectrum should be accessible and appropriate to their ethnicity. This will require proactive strategies.	C
3.	Providers of further and post-compulsory education should ensure that their members of staff are aware of the specific educational needs of autistic people.	C
4.	Work (paid and unpaid) should be considered an option for all autistic people, regardless of their intellectual ability. Any known support needs of autistic people, including cognitive ability, should be taken into account when transitioning into any work environment. Supported employment services for people on the autism spectrum should be developed (*see Appendix 3.3*).	B
4.	Vocational services of a high standard should be available to autistic people who are not ready or able to access post-compulsory education and work.	B
5.	All children and adults on the autism spectrum 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.	Person-centred planning should focus on individual choice and preference, including strengths, capacities, interests, and experiences. It should include recognition that people on the autism spectrum have a right to privacy, a right to culturally responsive services, and a right to be autistic.	B
7.	Leisure and recreation planning should be included in a student/young person's transition programme and this information shared with post-school providers.	C
8.	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
9.	People having regular contact with autistic children and young people should be screened for safety, and paid staff should be appropriately trained, supported, and supervised.	C
10.	Autistic people 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

Key recommendations for living in the community	Grade
11. If autistic people are abused, they should receive services from Oranga Tamariki, Victim Support, Accident Compensation Corporation (ACC Sensitive Claims Unit) and other similar agencies.	C
12. Families, whānau, carers and professionals should ensure that measures are undertaken during the childhood of the autistic person to prevent the characteristics of autism developing into behaviour that leads to victimisation or criminal offending.	C
13. Young people and adults on the autism spectrum 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
14. Autistic people involved in disputes within the Family Court are advised to seek assistance from solicitors and advocacy services with knowledge and experience in autism/takiwātanga.	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 autistic people/tāngata whaitakiwātanga.

Parents, specialists, education, health and other disability professionals and paraprofessionals who work or live with autistic individuals 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 autism/takiwātanga be coordinated nationally and standards and required competencies are 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 autism/takiwātanga.	C
2.	Education and training of local health care professionals in the administration of standardised autism/takiwātanga assessment interviews and schedules should be provided. When reporting the results of ASD-specific tests, caution should be exercised as Aotearoa New Zealand norms have not yet been established.	C
3.	Norms should be developed for ASD assessment tools specifically for the Aotearoa New Zealand population.	C
4.	Professional education curricula for people working in health, education and social services should include knowledge and awareness of particular issues that couples may experience when one or both partners is autistic.	C
5.	Social service staff members should have adequate education in child-welfare issues relating to autistic parents.	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 autism/takiwātanga and those agency procedures should incorporate best practices in autism.	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

Key recommendations for professional learning and development		Grade
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.	Professionals working with people on the autism spectrum and their families/whānau need professional learning and development in cultural responsiveness, particularly the impact of ethnic culture on practice.	B
13.	Identification, education, and support of autism consultant practitioners should be a priority in each region. Consultant practitioners should be skilled in evaluating programmes and translating research into practice.	✓
14.	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 takiwātanga. As a complement to this, five hui were conducted throughout Aotearoa New Zealand in 2005 to provide an opportunity for Māori to contribute their views and perspectives about takiwātanga. From these hui, a descriptive analysis identifying the main issues raised was undertaken. Recommendations were then developed based on the findings of the literature review and the main themes from the hui.

For this edition, expert consultant Associate Professor, Massey University (retired), Jill Bevan-Brown developed 11 additional Good Practice Points. These were derived from the content of Part 7 to give Māori perspectives more prominence.

Key recommendations for Māori perspectives		
1.	Information packages in appropriate and relevant language about takiwātanga 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 takiwātanga should be considered.	✓
3.	A programme of empirical research that would provide baseline information about Māori and takiwātanga should be developed.	✓
4.	Takiwātanga provisions for Māori tamariki, rangatahi, pakeke and their whānau should be culturally appropriate. This involves valuing and affirming their cultural identity by including Māori concepts, knowledge, skills, reo, processes, practices, resources, customs, attitudes, values, and beliefs.	✓
5.	People who work with tāngata whaitakiwātanga should possess the knowledge, skills and attitudes needed to provide culturally responsive, friendly and effective services. This includes valuing and supporting Māoritanga and Māori expertise.	✓
6.	Parents, whānau and, where appropriate, tāngata whaitakiwātanga themselves, should be consulted on an on-going basis and involved in all goal setting and decision-making relating them. This includes consultation about their needs and aspirations; areas of importance and concern; relevance and appropriateness of provisions and the nature and extent of cultural input preferred and involvement possible.	✓
7.	Takiwātanga-focused policies, reports, research, resource development and data collection should all include a Māori component.	✓

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 autism and Pacific Peoples should be developed.	✓
2.	A targeted recruitment and development strategy to support increasing the capacity and capability of the Pacific autism-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

There is no definitive information on the prevalence and incidence of autism in Aotearoa New Zealand. However, considering a range of estimates, it can be said that, conservatively, about 1–2% of the population are likely to be autistic; that is, between 50,000 and 100,00 autistic people/tāngata whaitakiwātanga in Aotearoa New Zealand.

Autistic people/tāngata whaitakiwātanga have often remained undiagnosed and unsupported in Aotearoa New Zealand communities.

There is ever-increasing awareness of autism/takiwātanga among health, education and social service professionals, parents, and the general community. A nationally consistent standard of practice for the assessment, diagnosis ,and meeting of support needs of autistic children, young people and adults aims to improve access to health, education and social services. It also provides a reliable evidence-based resource for autistic people and their families and whānau.

Te Tiriti o Waitangi

The Guideline acknowledges and upholds the principles of Te Tiriti o Waitangi/ Treaty of Waitangi. It considers the Treaty principles of partnership, participation, and protection central to improving health and education outcomes for Māori.

Consistent with Whāia Te Ao Mārama 2018–2022: The Māori Disability Action Plan,[32] the Guideline seeks to advance practices and services for tāngata whaitakiwātanga Māori that upholds the significance of te reo Māori, te Ao Māori (the Māori world), and ensure access to Māori approaches to practice.

This vision sees tāngata whaitakiwātanga Māori having leadership, genuine choice and control over the supports which enable them to thrive, flourish and live the life they want.

Enabling Good Lives

Enabling Good Lives[33] is a partnership between the disability sector and government agencies aimed at the long-term transformation of how disabled people and families are supported to live everyday lives. The primary focus is to enable disabled people and their families to have greater choice and control over the supports they receive and the lives they lead.

The funded model of EGL us currently not available across the whole country/motu, however Whaikaha - the Ministry of Disabled People are charged with leading this long term system transformation over the next few years. See: https://www.enablinggoodlives.co.nz.

Principles of Enabling Good Lives

Eight principles are the basis for all decisions and actions within this framework.

- **Self-determination**: Disabled people are in control of their lives.
- **Beginning early**: Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.
- **Person-centred**: Disabled people have supports that are tailored to their individual needs and goals, and that takes a whole life approach rather than being split across programmes.
- **Ordinary life outcomes**: Disabled people are supported to live everyday

life in everyday places. They are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation – like others at similar stages of life.

- **Mainstream first**: Disabled people are supported to access mainstream services before specialist disability services.
- **Mana enhancing**: The abilities and contributions of disabled people and their families are recognised and respected.
- **Easy to use**: The abilities and contributions of disabled people and their families are recognised and respected.
- **Relationship building**: Supports build and strengthen relationships between disabled people, their whānau and the community.

Characteristics of Enabling Good Lives

There are five characteristics of the Enabling Good Lives[33] approach.

1. Self-directed planning and facilitation

   All supports and services are led by the preferences, strengths, aspirations and needs of disabled people and their families. An aspiration-based personal plan is a central document to design and measure paid supports. While the core components of plans may be similar, plans make take different forms. Unique and changing aspirations are to be expected. Supports and services will need to continually adapt in the way they assist people to build and maintain a good life.

   An Independent Facilitator (Navigator) can assist disabled persons and family/whānau to consider existing options and create new possibilities. The degree of involvement an individual or family has with a Navigator is negotiated between the parties.

2. Cross-government individualised and portable funding

   Disabled people and family/whānau will have control of funding; i.e., bulk funding, according to service type, will be replaced with individualised funding where people can choose how they create a good life for themselves. All government funders will contribute to one funding pool that is determined through a simple process of self-assessment (or supported self-assessment) and confirmation.

   Eligible disabled people and family/whānau will be able to move their funding as their preferences and needs change.

3. Considering the person in their wider context, not in the context of ‘funded support services’.

   Disabled people and family/whānau belong to networks e.g., family, friends and community. These networks are respected as being fundamental to identity, belonging and citizenship.

4. Strengthening families or whānau

   There is a direct investment in the networks of disabled people and their families/whānau. Resources are provided to assist understanding, educate, and promote increased knowledge of options and how to maximise choice and control.

5. Community building to develop natural supports

   Disabled people are active and valued citizens with everyday life in everyday places. Enabling Good Lives[33] supports people to achieve desired outcomes such as education and training; employment; being with friends; having relationships and a family; and taking part in community and cultural activities. Community (generic, mainstream) opportunities and assets are educated and supported to be inclusive and valuing of diversity.

Definitions

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,[29] all people who are diagnosed with ASD share characteristics in two domains: challenges in social communication or social reciprocity, and restricted, repetitive patterns of behaviour. The newly applicable ICD-11 is similar (*see Appendix 4*).[39] Both classifications also point to the importance of examining unusual sensory sensitivities, which are common among people on the autism spectrum.

Although these features are characteristic of all autistic people/tāngata whaitakiwātanga, it is a very heterogeneous condition affecting a very diverse group of individuals with a wide range of support needs, disabilities, communication abilities and intellectual ability. The diverse support needs expressed by people across the autism spectrum require that a wide range of services and approaches be employed.

The Guideline's first edition was prescient in recognising the movement toward considering autism as a spectrum condition. In the latest edition of the diagnostic manual DSM-5,[29] four pervasive developmental disorder subcategories (specified in the manual's predecessor, the DSM-IV)[30] 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 implications of the DSM-5[29] for the Guideline were considered by the Living Guideline Group in their Supplementary Paper[19] (summarised in Appendix 3.5). In this edition of the Guideline, references to previously used diagnostic subtypes have been retained where they reflect their application in research studies. The Living Guideline Group advise that, given the DSM-5,[29] where the diagnostic terms Asperger syndrome and PDD-NOS are used in the Guideline they should be read as referring to autism, or the diagnosis of ASD where appropriate. See the 'Autistic perspectives' section.

Neurodiversity

The term ‘neurodiversity’ was coined in the late 1990s by autistic Australian sociologist Judy Singer to recognise natural neurological variations in how the human brain works.[34] These variations are not considered deficits but natural differences compared to ‘neurotypical’ or typical neurological patterns. Neurodiversity includes both life-long conditions and those that can develop throughout life, including autism, Attention Deficit Hyperactivity Disorder (ADHD), dyscalculia, dyslexia, dyspraxia, dysgraphia, and Tourette syndrome, among others.

The concept of neurodiversity represents a strength-based model where autism/ takiwātanga is considered not something to be cured, but rather a way of being with both challenges as well as strengths that can make a unique and positive contribution to society.[19] Highlighting the positives of neurodiversity has the potential to increase awareness and understanding of neurological differences while also reducing social stigma.[35]

Autistic perspectives

Many in the autistic community are uncomfortable with the acronym ASD. This is because the word ‘disorder’ conveys a sense of autism as a pathological impairment rather than a reflection of neurodiversity.[36]

In response to such concerns, ASD is sometimes defined as autism spectrum *difference* rather than *disorder*. And in the UK, the term Autism Spectrum Condition (ASC) is sometimes used.

However increasingly people in the autistic community prefer to use identify-first language by referring to themselves as autistic (and less commonly, as autists or neurodivergent). The Autism Self-Advocacy Network (ASAN) suggest that this recognises autism as a central part of one’s identity – of who one is, rather than as something separate to oneself, that can be put aside (as implied by being ‘with autism’). Moreover, ASAN suggests that whilst an autistic person has support needs, autism itself “does not equal disability, disability is what someone experiences when they interact with a society that cannot reciprocate or accommodate them” (see: https://www.asan-au.org/autistic-the-word/)

These changing preferences are confirmed by a 2020 Australian study of 198 adults which found the terms ‘autistic’, ‘person on the autism spectrum’, and ‘autistic person’ rated as most preferred and least offensive, with ‘person on the autism spectrum’ ranked the most preferred term overall.[37]

This new edition provides the opportunity to incorporate changes in language that best reflect current community preferences. The terms ‘autistic person’ and ‘person on the autism spectrum’ are used to refer to someone understood to meet the criteria for the diagnosis of Autism Spectrum Disorder. The acronym ASD is used when referring to a person’s clinical diagnosis, or diagnostic tools or services. It is understood that language preferences may continue to evolve.

Fundamentally, autistic individuals have the right to self-refer and are referred to as they choose.

It is understood that the terms 'high functioning' and 'low functioning' to describe groups of autistic people are considered unhelpful and divisive by many on the autism spectrum.[Ref_38] Instead, people are considered to vary in terms of the level and complexity of their support needs. 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-scale IQ scores of 70 or above), or through the diagnosis of 'high-functioning autism' or Asperger syndrome (under DSM-IV criteria).[30] Where 'high functioning' is used in this context, it does not mean that an individual does not have support needs, but their needs may instead be less obvious to others.

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.[29] Notably, under the DSM-5, whether autism and intellectual disability occur simultaneously is recognised through the use of 'specifiers, whereas the ICD-11's classification[39] provides detailed guidelines for distinguishing between autism with and without an intellectual disability (*see Appendix 4*).

An additional revision for the third edition was to replace the terms 'problem behaviour' and 'challenging behaviour' with 'behaviour of concern'. The use of 'problem behaviour' can be perceived as implying the autistic individual is deliberately doing something wrong or 'being naughty' or 'difficult'. However the behaviour is the problem, not the person, and the challenge lies in how to support them. The behaviour may be a concern to the autistic individual (such as self-harm) or it may only be a concern to others who do not understand its purpose (e.g., shutdown from sensory overload). Addressing this concern, therefore, does not necessarily imply the need to eliminate or replace the behaviour. In specific situations, where possible, the behaviour should instead be described with respect to the autistic person's experience (e.g., sensory overload, stimming, expression of distress).

Other problematic terms refer to autistic people who can reliably use speech to communicate as being 'verbal', and those who do not as being 'non-verbal'. However, verbal language is not just speech. It is a system of conventional symbols that have shared meaning for members of a community or culture who use a common language,[40] and can therefore include spoken and written words, signs or visual codes. To avoid confusion, some autistics prefer the terms 'speaking' and 'non-speaking'. For some individuals, however, this does not reflect that their ability to speak can change over time depending on its purpose and content, the relationship with conversational partners, and access to augmentative and alternative communication (AAC) systems. To be more inclusive, alternative terms sometimes used include 'minimally speaking', 'unreliably speaking', or having 'complex communication needs (CCN)'. In the Guideline, we refer to people who 'have speech' as those who can consistently rely on speech for functional communication. However, it's always best to ask a person what terms work for them for inclusion in support plans, based on their own lived experiences and identity.

Note that non-verbal means something different when describing non-symbolic communication such as body language, facial expressions, tone of voice, and eye gaze to convey meaning.

Examples of other language changes for the third edition aimed at depathologising the condition include replacing the term 'comorbidity' with 'co-occurring'; 'normal' with 'non-autistic'; 'symptoms' with 'characteristics'; 'special interests' by 'focused interests' or 'intense interests'; and the terms 'impairments' and 'deficits' with 'challenges' and 'difficulties'. Terms relating to 'treatment' and 'management' have been generally avoided, particularly where they relate to the nature and expression of autism itself. Instead, they have been replaced by 'supports' and 'supportive approaches'.

This is consistent with a strengths-based neurodiversity perspective and the 'right to be autistic'. The new Good Practice Point 4.3.13 (Key recommendation 7 in Part 4) exemplifies this philosophy. It sets out guidance for individuals and whānau in choosing a supportive approach, strategy, practitioner or therapist to ensure principles for ethical practice are followed.

Māori perspectives

Takiwātanga is a Māori word for autism. This term was coined by Keri Opai after consultation with tāngata whaitakiwātanga (autistic people). It means 'in my/their/his/her own time and space' and, as Opai notes, it reflects "a positive, Māori worldview aspect of autism".[41]

'Tangata whaitakiwātanga' refers to an autistic person.

'Tāngata whaitakiwātanga' refers to autistic people.

However, every individual's right to self-refer and be referred to as they choose should be respected.

Other terms for autism are sometimes used (such as kura urupare, meaning 'gift of Sensories'). However, takiwātanga has become sufficiently established that the Living Guideline Group approved its use in this edition of the Guideline.

The Māori terms for neurodiversity are 'kanorau ā-roro' (kanorau =diversity, ā-roro=of the brain) and 'kanorau ā-io' (kanorau =diversity, ā-io=of the nerves).

Māori cultural concepts and values not only determine how takiwātanga is perceived but also attitudes towards it and how autistic whānau should be supported. Sir Mason Durie[42] provides a helpful framework to guide services and programmes for tāngata whaitakiwātanga and their whānau. Durie's Whare Tapa Whā model lists four dimensions of wellbeing for Māori. These are taha tinana (physical wellbeing); taha hinengaro (mental wellbeing); taha wairua (spiritual wellbeing) and taha whānau (family wellbeing). Consequently, to be culturally responsive, provisions for tāngata whaitakiwātanga need to incorporate these four dimensions.

Another framework that complements Te Whare Tapa Whā, is Ka Hikitia's Outcome Framework. Ka Hikitia is Aotearoa New Zealand's Māori Education Strategy which is based on extensive consultation and focused on achieving "excellent and equitable outcomes" for Māori.[43] The Good Practice Points in Part 7 of this Guideline are actionable strategies that support Ka Hikitia's goals and principles and fit well within the five domains of its Outcome Framework. These are:

- Te Whānau: education provision responds to Māori within the context of their whānau
- Te Tangata: Māori are free from racism, discrimination, and stigma
- Te Kanorautanga: Māori are diverse and need to be understood in the context of their diverse aspirations and lived experiences
- Te Tuakiritanga: Identity, language and culture matter for Māori
- Te Rangatiratanga: Māori exercise their authority and agency.

Prevalence

There is no definitive information on the prevalence and incidence of autism in Aotearoa New Zealand. The CDC estimate is as high as 2.3% based on children aged 8 years in the United States.[44] However a recent systematic review of 99 prevalence estimates from 71 epidemiological studies by Zeidan et al (2022) found the median prevalence was 100/10,000 (1%), range: 1.09–436.0/10,000.[45] This accords with Aotearoa New Zealand research from linked case data sets suggesting that 1 in 102 8-year-olds were autistic.[47]

It is understood that prevalence figures vary due to variable case definitions and determination, reliance on parental reports, case ascertainment through mainstream school surveys, and the effect of age and culture in interpreting survey results.[46] Given the diverse range in estimates reproted internationally, and the steady increases observed in the CDC data, a conservative estimate of 1–2% prevalence of autism/takiwātanga seems reasonable. This translates to between 50,000 and 100,000 autistic people living in Aotearoa New Zealand in 2022.

Boys are affected about 4 times more frequently than girls (median estimate=4.2), however the range of ratios is very wide (0.8–6.1).[45] Consistent with this, a ratio of 4.59 to 1 males to females on the autism spectrum was observed in the Aotearoa New Zealand study.[47] Theories have suggested that autism has been systematically under-diagnosed in females across the age span.[48-50] Some studies attribute sex differences to 'boy-centric' aspects of diagnosis such as girls having more socially appropriate restricted interests than boys, or overall higher levels of social skills, or lower IQ.[45] The impact of ascertainment issues on prevalence estimates are currently unknown.

There is a need for earlier and more accurate identification of autism. The earlier the condition is diagnosed, the sooner the child can be helped with supports. Sadly, delays in diagnosis are common, and many adults may not have received a formal diagnosis. Without adequate services for autistic individuals across health, education and social inclusion, Aotearoa New Zealand will lose the potential benefits of these individuals as well as increasing difficulties for their families.

There are currently international indications that the incidence of autism may be rising. It is not clear whether this change is due to an actual increase in incidence, increased awareness, or changes in the 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 autism, including diagnosis and assessment, educational provision and other approaches, strategies, or therapies 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 autistic individuals. Throughout the 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, education, social and all other relevant aspects are considered.

Impact analysis

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 to identify 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 Guideline.

Legislation

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

Relevant health, disability and education legislation and policies

Legislation and standards

- Treaty of Waitangi/Te Tiriti o Waitangi
- 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
- Public Records Act 2005
- Public Service Act 2020

- Official Information Act 1982
- Privacy Act 2020
- Education and Training Act 2020
- Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003
- Health and Disability Commissioner Act 1994
- Code of Health and Disability Consumers' Rights 1996
- The Oranga Tamariki Act 1989 or Children's and Young People's Wellbeing 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 (UNCRPD) 2008[31]
- United Nations Convention on the Rights of the Child (UNCROC) (1989)
- Children's Act 2014

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 Tāhuhu: Improving Mental Health 2005–2015: The Second New Zealand Mental Health and Addiction Plan
- Disability Action Plan
- Child and Youth Wellbeing Strategy
- Learning Support Action Plan
- Ka Hikitia
- Pacific Education Plan
- The Statement of National Education and Learning Priorities (NELP)
- Tertiary Education Strategy (TES)

Reports

- Curry Report 1998
- Werry Report 1998
- Whāia Te Ao Mārama: The Māori Disability Action Plan[32]
- 'Ala Mo'ui: Pathways to Pacific Health and Wellbeing
- Faiva Ora National Pasifika Disability Plan
- Disability Strategy Implementation Plan
- Living with Disability New Zealand 2001 Post Census Disability Survey
- Making Disability Rights Real[51]
- Poipoia ngā akonga kanorau ā-roro[52]
- Responding to neurodiversity in the education context: An integrative literature review[53]
- Inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia, and autism spectrum disorders in primary and secondary schools (2016)[54]

Implementation

Improvement in outcomes for autistic individuals 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

Diagnosis and initial assessment

“Ma te mohio ka marama”

Through knowledge there is understanding

Part 1: Diagnosis and initial assessment

This part of the Guideline covers the principles of identification, diagnosis, and initial assessment of autistic individuals.

The earlier the diagnosis of autism/takiwātanga is made, the more impact early supportive approaches, strategies, or therapies have, resulting in fewer 'behaviours of concern' and better outcomes for families.[55] For 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. A referral is usually to a paediatrician, a child development service, or a specialised early intervention service provider.
- Ages 4 to 8 years – children who present at this age may have less apparent characteristics of autism 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), Learning Support Coordinators (LSCs), Resource Teachers of Learning and Behaviour (RTLBs), Ministry of Education, Learning Support, or paediatricians. Occasionally, they may present via the courts.

Although early support programmes may have been undertaken because of concerns about learning and development, most children require a diagnosis to access appropriate education modalities and support programme services and to assist the family/whānau with appropriate information to plan their lives. It is therefore essential to diagnose those children with autism early to provide early support programmes 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.[55] Experienced clinicians can make the diagnosis in autistic children with clearly presenting high/complex support needs by the age of two or three years. Whereas children with less obvious support needs may not be identified until they are at early childhood education services or school. These children may have more advanced communication skills but can still have significant needs.

Much of the literature on autism centres on the early diagnosis and early intervention of young autistic children. However, there are also undiagnosed young people and adults on the autism spectrum. Some seem to manage well[56, 57] while other undiagnosed people and their families and whānau endure great stress, and they can be misunderstood, blamed, teased, bullied, poorly supported and miss out on effective support options,[58] or receive inappropriate medical, psychiatric, and educational support programmes. Some receive psychiatric or intellectual disability services or both, yet without the recognition of their autism/takiwātanga, services are not appropriately tailored to their individual needs (*see Part 4, section 4.8: Mental health, forensic and disability services*). For some individuals who have not received a formal 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 Part 5, section 5.3: Contact with the justice system*).

Autism advocacy agencies,[59] professionals[56-58, 60] and published accounts by autistic people/tāngata whaitakiwātanga[61, 62] suggest that the assessment and diagnosis of young people and adults on the autism spectrum are important because it:

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

Formal criteria for the identification and diagnosis of autistic people/tāngata whaitakiwātanga are provided in Appendix 4 concerning the fifth edition of the Diagnostic and Statistical Manual for Mental Disorders, the DSM-5.[29] Implications of these revised criteria for the original edition of the Guideline were considered by the Living Guideline Group and are summarised in Appendix 3.5.

1.1 Identification and diagnosis

Summary of recommendations

Recommendations and Good Practice Points:		Grade
1.1.1	Early identification of autism is essential. Early identification enables early introduction of support programmes 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 autism 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 condition, should be collected and audited. This data should include ethnicity. Where disproportionate ethnic representation exists, reasons for disparities should be investigated and addressed (*see Appendix 3.8*).	C
1.1.5	Parental inquiries regarding developmental concerns about their child must be taken seriously and addressed appropriately.	B
1.1.5a	Diagnosticians should be aware of the potential for bias based on ethnicity which may lead to delayed diagnosis or misdiagnosis (*see Appendix 3.8*).	B
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 autistic children 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 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 the implementation of a population-screening tool for the identification of autistic people/tāngata whaitakiwātanga[14] (*Recommendation 1.1.2*). Their findings supported the consensus that parents or professionals with knowledge of typical (non-autistic) development can identify autism. Early identification of takiwātanga 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.[63] 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 autistic children, best practice in Aotearoa 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).[63] This requires that all professional encounters with young children, including contacts with day-care providers and early childhood teachers, should be viewed as opportunities to elicit developmental information and concerns (*see Recommendations 1.1.3 and 1.1.4, Good Practice Points 1.1.6 and Recommendation 6.1: Professional learning and development, and Good Practice Points 7.5 and 8.7 regarding research data for Māori and Pacific Peoples).*

Although many parents are aware by 18 months that their child is different, the formal diagnosis of autism has often been delayed in the past.[64] 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.[65] Although skilled community health and education staff can assist parents in the recognition of an area of concern, 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'.[65] Although similar information is unavailable in Aotearoa New Zealand, the experience of those working in the area of autism/ takiwātanga suggests that the situation is likely to be no different.

Studies[66-68] 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 have less obvious support needs, and in those with significant general developmental delay (e.g., a 'mental age' below one year).

The opinion of the committee which developed the NAPC (National Action Plan for Children) in the United Kingdom, supported by experience in Aotearoa New Zealand, is that there have been several barriers to early diagnosis.[14] These include: failure to recognise characteristics of autism, 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 autism in young children and the effectiveness of support programmes are dependent on the ability of primary care providers to monitor children's development and initiate referrals promptly. 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 autism (*Recommendation 6.1: Professional learning and development*).

Eliciting, valuing, and addressing parental concerns

Parents of autistic children often note characteristics 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.[69] While a small number of children do 'catch up' without formal support programmes, this approach will delay the identification of and support for autistic children who could substantially benefit from earlier identification and support (*Recommendation 1.1.5*). Diagnosticians should also be aware of the potential for bias based on ethnicity which may lead to delayed diagnosis or misdiagnosis (*see Recommendation 1.1.5, and Appendix 3.8 relating to the update on ethnicity undertaken through the Living Guideline process*[22]).

Assuring appropriate referral of a child who is possibly autistic

Throughout Aotearoa New Zealand there is no consistent referral and assessment pathway for autistic children (or indeed children with other developmental conditions). Multiple potential referral points exist, such as Child Development Services or Ministry of Education, Learning Support, 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 characteristics (*Good Practice Point 1.1.7*).

There are genetic factors in the causation of autism/takiwātanga, 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 characteristics of autism. These include fragile X, Rett syndrome and tuberous 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 characteristics and delays 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, the 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 autistic children 1–3 years **C**

All children with ANY of the following findings MUST be referred for a general developmental assessment:

- no babble, pointing to or showing of objects or other gesture by 12 months
- no meaningful single words by 18 months[70]
- no two-word spontaneous (non-echoed or imitated) phrases by 24 months
- ANY loss of any language or social skills at ANY age.[71]

Key signs in children aged 1–3 years (which should prompt referral for a developmental assessment, modified from the NAPC Guideline):[14, 68]

Social impacts:

- lack of social smile and lack of eye contact
- lack of imitation of actions (e.g., clapping)
- difficulties in joint attention, such as lack of showing to share interest or involving others in joint play with toys or other objects
- lack of interest in other children or odd approaches to other children
- minimal recognition or responsiveness to another's happiness or distress
- not wanting to be picked up and cuddled
- atypical relationships with adults (either too friendly or distant)
- limited variety of imaginative play
- lack of pretend play, especially involving social imagination (i.e., not joining with others in shared imaginary games)
- appearing to be 'in his/her own world'
- failure to initiate simple play with others or participate in early social games
- preference for solitary play activities.

Communication impacts:

- difficulties in language development, especially comprehension
- unusual use of language
- poor response to name
- limited non-verbal communication (e.g., lack of pointing and difficulty following the pointing of others)
- failure to smile socially to share enjoyment and respond to the smiling of others
- atypical 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
- limited use of language for communication and/or tendency to talk freely only about specific topics.

Table 1.1: Key signs for identification of autistic children 1–3 years	C

Impacted interests, activities and other behaviours:

- over-liking for sameness and/or inability to cope with changes especially in unstructured settings
- repetitive play with toys (e.g., lining up objects or turning light switches on and off, regardless of scolding)
- over-attentiveness to small visual details (e.g., fascination with spinning wheels)
- repetitive motor mannerisms
- 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)
- difficulty in organising self in relation to unstructured space (e.g., hugging the perimeter of playgrounds, halls).

Other factors which may support a diagnosis of ASD:

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

Note: These factors in isolation are not indicative of autism. They are intended to alert professionals to think about the possibility of autism – whether and when they make a referral will depend on the overall situation.

Children aged 4 to 8 years

For autistic children with less obvious challenges, professionals may not express concerns until those children are exposed to the greater social demands of early childhood education or primary school. Whilst for other undiagnosed autistic children, professionals may not suggest an autism assessment until the complex and changing social demands of high school. Indeed, prior to school entry, some may have been thought to be well advanced in their development, because of their intense focused interests and precocious vocabulary.

The following autistic characteristics should alert teachers and others to the possibility of autism/takiwātanga. The features described for younger children are also applicable to this age group. The presence of these characteristics should trigger a discussion with parents and the possible implementation of the local referral pathway.

Table 1.2: Key autistic characteristics in children aged 4–8 years
(modified from the NAPC Guideline)[14]

C

1. **Communication impacts:**
   - affected 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
   - limited use of language for communication and/or tendency to talk freely only about specific topics.

2. **Social impacts:**
   - inability to join in with the play of other children, or inappropriate attempts at joint play (may manifest as aggressive or disruptive behaviour)
   - lack of awareness of classroom ‘norms’ (criticising teachers; overt unwillingness to cooperate in classroom activities; inability to appreciate/follow current trends, e.g., about other children’s dress, style of speech, interests etc)
   - easily overwhelmed by social and other stimulation
   - atypical in relating to adults (too intense/no relationship)
   - showing extreme reactions to the invasion of personal space and extreme resistance to being ‘hurried’.

3. **Impacts on interests, activities and behaviours:**
   - lack of flexible, cooperative imaginative play/creativity (although certain imaginary scenarios, e.g., copied from videos or cartoons, may be frequently re-enacted alone)
   - difficulty in organising self in relation to unstructured space (e.g., hugging the perimeter of playgrounds, halls)
   - averse to change or unstructured situations, even ones that other children enjoy (such as school trips, teachers being away, etc)
   - preoccupation with restricted patterns of interest that are atypical either in intensity or focus; over-attention to parts of objects.

4. **Other factors which may support a diagnosis of ASD:**
   - unusual profile of skills/deficits challenges (e.g., social and motor skills very poorly developed, whilst general knowledge, reading or vocabulary skills are well above chronological/‘mental’ age)
   - any other evidence of unusual behaviours, including over-or-under-sensitivity to sound (e.g., has trouble functioning when there is noise around), touch (e.g., difficulties standing in line or close to others, avoids getting messy, or excessively touches people and objects), movement (e.g., avoids playground equipment or moving toys, or seeks all kind of movement, and this interferes with daily routines), visual stimuli (e.g., prefers to be in the dark, discomfort or avoids bright lights) or smells (e.g., deliberately smells objects)
   - unusual responses to movement (e.g., toe walking and hand flapping)
   - unusual responses to pain
   - any significant history of loss of skills.

No criteria were provided in the NAPC Guideline[14] to guide referral for diagnosis in children older than eight years. Guidance for the 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:[69, 72]

- changes in characteristics of autism 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 impacts – where the differences in social behaviour between the person in question and same-age peers have 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, culture, 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 prompt referral for diagnosis of adolescents and adults with lower/less obvious support needs (including those who could be diagnosed with high functioning autism (HFA) or Asperger syndrome (AS) under the DSM-IV) (*see Definition in the 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 condition that may be autism/takiwātanga through to making a diagnosis.

Summary of recommendations

Recommendations and Good Practice Points:		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 autism should undertake diagnostic assessment of young people and adults suspected of being autistic. In the absence of an assessment team, a health care practitioner trained and highly experienced in the autism spectrum 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 (*see Appendix 3.5*).	C
1.2.5	Standardised ASD assessment interviews and schedules should be used (*see Appendix 3.5*).	B
1.2.6	Test users should ensure that they are aware of the validity, reliability and appropriateness of tests when assessing autistic people and take these limitations into account when forming opinions and reporting results.	C
1.2.7	The intellectual, adaptive, and cognitive skills associated with autism/takiwātanga should be seriously considered and, where possible and appropriate, formally assessed.	B
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 autism or another developmental concern should have an audiology assessment.	✓

Recommendations and Good Practice Points:		Grade
1.2.11	If the general developmental assessment suggests autism, 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 Aotearoa 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 an action plan to meet the identified needs.

As autism is a developmental condition, the presentation will vary with age and, in any one individual, vary over time. The characteristics of autism/takiwātanga may be more prominent at some ages than others. A clear understanding of typical (non-autistic) social, behavioural and language development is required among parents, carers and professionals.[14]

The assessment has three specific aims:

- to identify the 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 the 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/wairua needs) are being taken into account.

From knowledge of current practices and services within Aotearoa New Zealand, there is currently inconsistent and inequitable access to the assessment.[1]

1.2.a Early childhood to adolescence

The recommended pathway leading to the assessment of a young child, older child or adolescent with suspected autism/takiwātanga 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 Aotearoa 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 typical (non-autistic) 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 (e.g., a speech-language therapy screening assessment) or informal (e.g., 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 concerns. 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 autism service coordination

A developmental services coordinator (DSC) appointed by Te Whatu Ora Health New Zealand 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 the Ministry of Education, Learning Support 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 conditions which need timely assessment.

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

- If a medical problem has been identified, a 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, Ministry of Education, or Learning Support 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 occasion, 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:
  - Te Whatu Ora Health New Zealand child development service
  - Ministry of Education, Learning Support
  - other specialised early intervention provider
  - Child and Adolescent Mental Health Services

  - non-governmental organisation (NGO) provider (e.g., 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 a diagnosis of 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 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 autism 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 Te Whatu Ora Health New Zealand for policy and planning purposes. Data to be collected include:
  - parental report of the age of first developmental concerns
  - age at referral to the coordinator or 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:
  - autism spectrum disorder diagnosis, or another diagnosis
  - presence of co-occurring conditions
  - level of verbal and non-verbal developmental function.

Note: It is not intended that an autism/takiwātanga or developmental condition register be established, but rather that the efficiency of service provision and service gaps be identified by data collection (recognising that data collection by disability is an obligation under the UNCRPD).[31]

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 the 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. 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, Learning Support, 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 from 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[14] has defined the following essential components of specialist team assessment. These have been adapted for Aotearoa New Zealand.

Essential components for a complete multiagency assessment

Existing information from all settings should be gathered.

- A specific autism spectrum 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 autism/takiwātanga 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 a 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 in 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 gestures. It also allows 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 children with language (i.e., through speech and/or augmentative and alternative communication), the assessment may also include a formal or informal child interview to provide further information

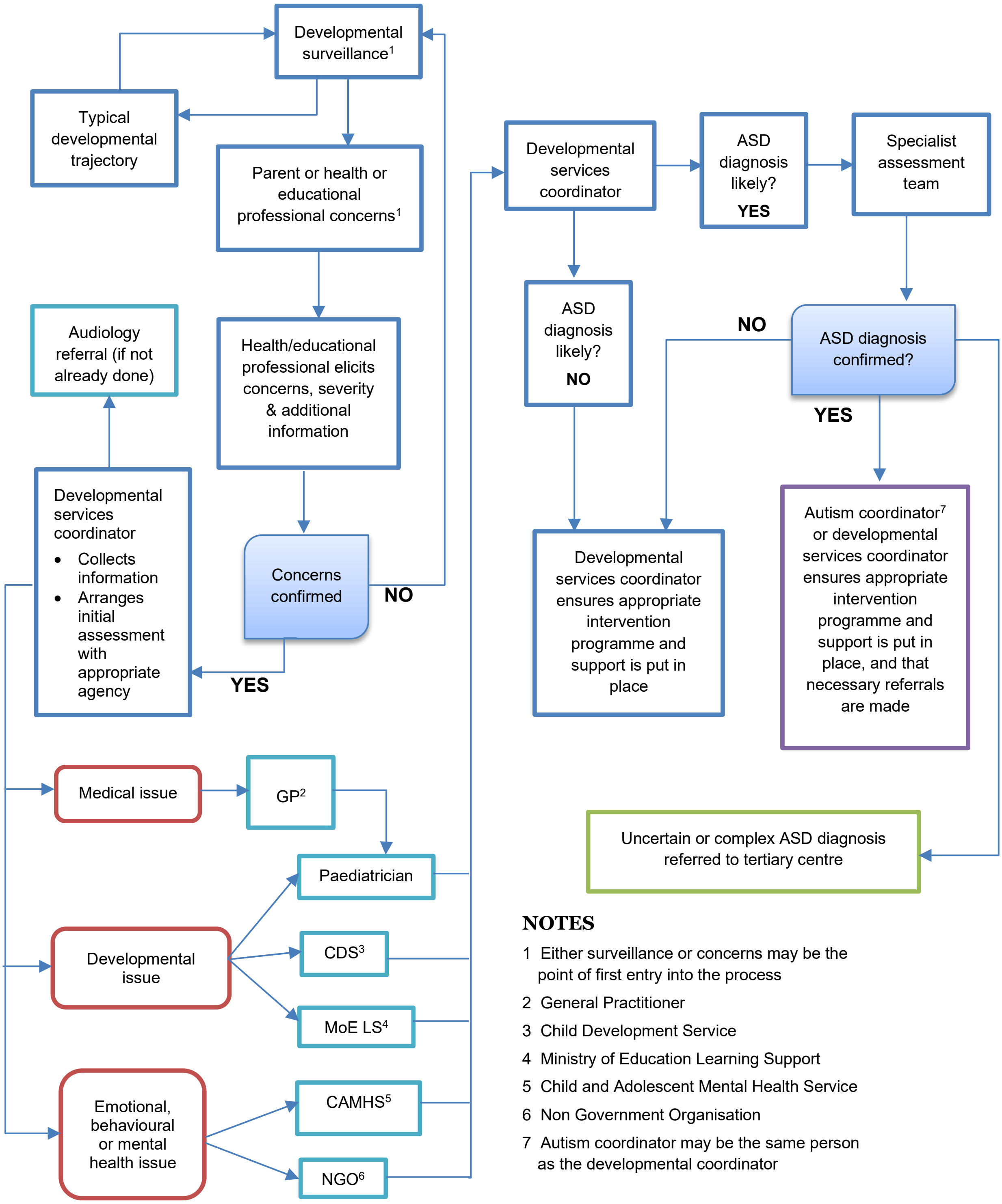
on pragmatic skills and diagnostic features of communicative style.

- If possible, a cognitive assessment should be performed in an appropriate setting by either a clinical or an educational psychologist with autism spectrum-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 autism spectrum-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-occurring mental health and behaviour challenges 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-occurring 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 difficulties. These assessments should be carried out by a therapist with appropriate experience in autism assessment. 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/supports, review of the child and provision of a comprehensive report.

After the assessment is completed, the DSC (or autism 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 be autistic



NOTES

1 Either surveillance or concerns may be the point of first entry into the process

2 General Practitioner

3 Child Development Service

4 Ministry of Education Learning Support

5 Child and Adolescent Mental Health Service

6 Non Government Organisation

7 Autism coordinator may be the same person as the developmental coordinator

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 being autistic[14, 69, 72-75] (*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 the autism spectrum is recommended for older individuals.[69] In Aotearoa New Zealand, recommendations and proposals have been made for the development of specialist ASD services that could undertake this role for autistic people/tāngata whaitakiwātanga of all ages,[76-78] but they have not been implemented.

Currently, within Aotearoa 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 autism/takiwātanga, and identifying autism spectrum 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 appropriate recommendations from within the Autistic 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 be autistic 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.[69, 79] Diagnosing people from these age groups presents several challenges, however, which include:

- recognising the wide range of expression of the characteristics of autism which are influenced by the person's level of maturity, lifetime experiences and cognitive ability[46]
- the likelihood of a more complex differential diagnosis because of the increasing possibility of alternative diagnoses and co-occurring conditions[79]
- competing diagnoses which may overshadow the diagnosis of ASD
- difficulty obtaining accurate and detailed early developmental history as the age of the individual increases.[57, 69]

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, 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 to better understand the person's abilities (note that professional tests users should be aware of ASD norms for the Vineland adaptive behaviour scales[80] and other autism relevant research)[81-83]
- 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[57, 69, 74, 75, 84-88] (*Recommendation 1.2.4*).

The use of standardised interviews and assessment formats for autism, Asperger syndrome and ASD is supported,[89] and assessment processes are regularly reviewed and refined as an understanding of autism develops further[90-93] (*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 being autistic or having other pervasive developmental disorders[92, 94-96]
- 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 being autistic or of having other pervasive developmental disorders[92, 97, 98]
- Asperger Syndrome Diagnostic Interview, a clinician-administered tool for use with children and adults suspected of having Asperger syndrome or High Functioning Autism[99]
- Autism Spectrum Disorder Screening Adults Questionnaire (ASDASQ), a screening test for ASD in the adult population[100]
- Autism Spectrum Quotient (AQ), a self-administered screening test for people suspected of High Functioning Autism/Asperger syndrome[101]
- Australian Scale for Asperger's syndrome (ASAS), a checklist for parents of primary school children suspected of having Asperger syndrome[102]
- Childhood Asperger Syndrome Test (CAST), a parent-completed screening test for children aged 5–11 years[103]
- Developmental, Diagnostic and Dimensional Interview (3di), a computerised assessment for autism spectrum disorders[104]
- Diagnostic Interview for Social and Communicative Disorders (DISCO), a clinician-administered schedule of assessment for use with people of all ages[105, 106]

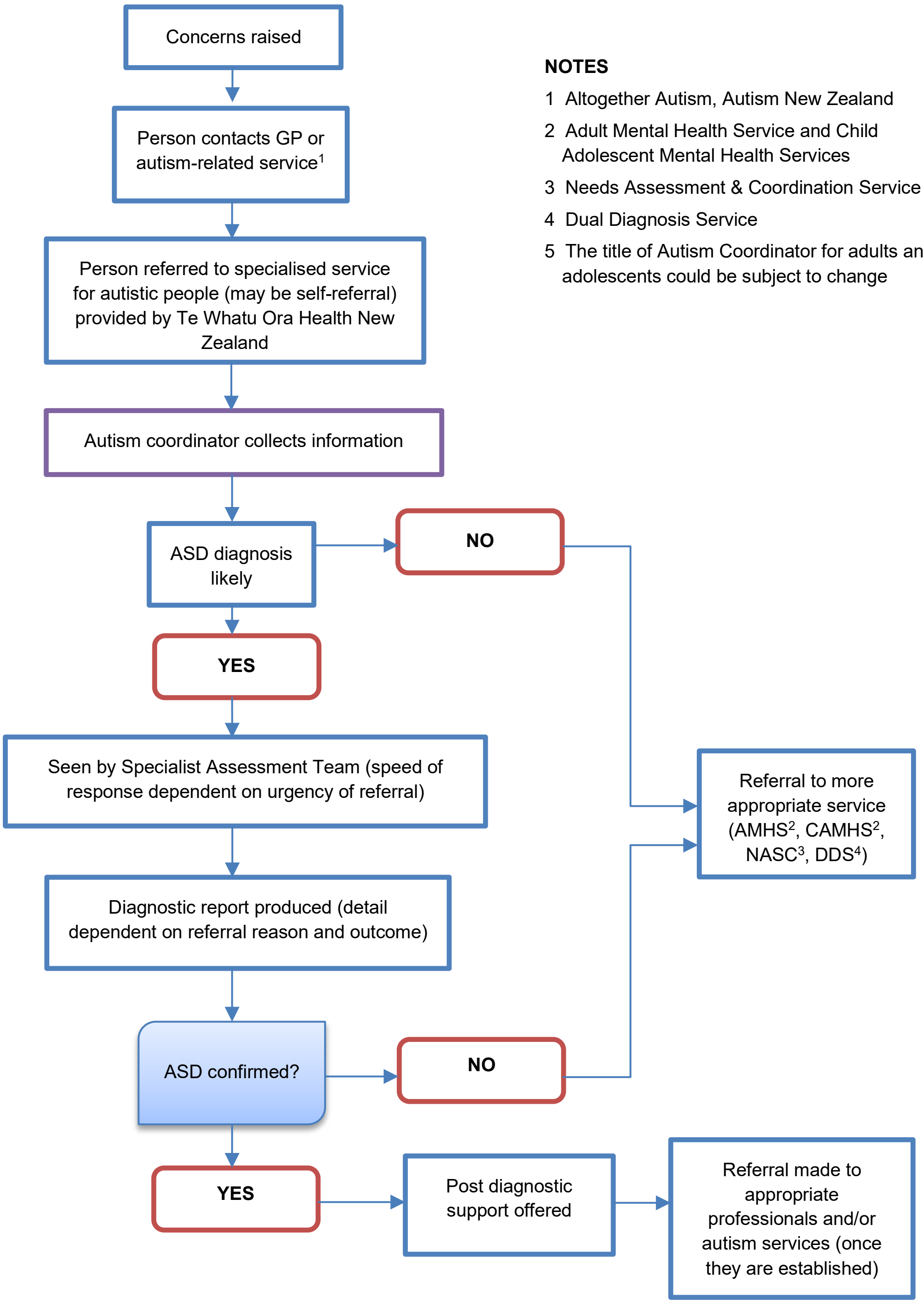
- Gilliam Asperger's Disorder Scale (GADS), a scale for use by parents and professionals, assessing Asperger syndrome in people aged 3–22 years[107]
- Krug Asperger's Disorder Index (KADI), a scale for use by professionals, assessing Asperger syndrome in people aged 6–22 years.[108]

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 Aotearoa New Zealand (*Recommendation 1.2.6, Recommendation 6.2: Professional learning and development*).

Assessment of specific cognitive abilities may lead to a fuller understanding of an individual's strengths and needs and, in turn, inform supports[109] (*Recommendation 1.2.7*).

No studies were identified which addressed the validity of applying any of the measures listed above to the Aotearoa New Zealand population. As no Aotearoa New Zealand norms have been published, information is lacking on the applicability of these tools to New Zealanders of any ethnic background and 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 be autistic



NOTES

1 Altogether Autism, Autism New Zealand

2 Adult Mental Health Service and Child Adolescent Mental Health Services

3 Needs Assessment & Coordination Service

4 Dual Diagnosis Service

5 The title of Autism Coordinator for adults and adolescents could be subject to change

1.3 Differential diagnosis of autism and consideration of other possible conditions

Summary of recommendations

	Recommendations and Good Practice Points:	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 a diagnosis of ASD and those known to coexist with autism.	C
1.3.3	Health care professionals must have a good understanding of the different forms of expression of characteristics of autism across developmental stages and the symptomatology of common co-occurring and alternative conditions.	B
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 who may potentially be autistic to fully consider other possible diagnoses (the differential diagnosis)[84, 110] (*Recommendation 1.3.1*).

When a child is being assessed for autism/takiwātanga, 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, and neglect.

These disorders may also occur in association with autism. Other conditions occur more commonly in association with autism/takiwātanga than in the general population. When two different conditions occur together in the same individual, they are called co-occurring conditions. In addition to the diagnoses listed on the previous page, they include:

- attention deficit hyperactivity disorder
- anxiety disorders, including Obsessive-Compulsive Disorder (OCD)
- Tourette syndrome
- depression
- developmental dyspraxia/ developmental coordination disorder
- epilepsy
- nutritional deficiencies secondary to a restricted diet
- specific 'intellectual disability'.

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

An increasing number of specific medical conditions have been described as being associated with the characteristics of autism. These include:

- degenerative neurological or metabolic condition
- Down syndrome
- Fetal Alcohol Spectrum Disorder
- Fragile X
- Rett syndrome
- tuberous sclerosis.

Every child with a developmental concern 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 supported by a paediatrician. Children with complicated or refractory epilepsy should have an evaluation by a paediatric neurologist.

Pharmacotherapy in autism and for other co-occurring conditions in association with autism/takiwātanga is discussed in Part 4, 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.[57, 69, 79, 111] Common differential diagnoses and/or coexisting conditions include schizophrenia, borderline personality disorder, intellectual disability, catatonia, depression, anxiety disorders, obsessive-compulsive disorders, attention disorders, language disorders, disorders of impulse control, and substance abuse.[30, 69, 84, 85]

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 assessing ASD, including an understanding of the different forms of expression of characteristics of autism/takiwātanga across developmental stages and the symptomatology of common co-occurring 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 a careful examination of the factors that prompted the referral
- collecting detailed history to discern whether potential signs of autism present at the time of assessment were present (albeit possibly in different forms) at earlier stages of development
- careful delineation of characteristics consistent with autism/takiwātanga, from characteristics of coexisting or alternative diagnoses[69] (*Recommendation 1.3.2*).

Note: the latest edition of the Diagnostic and Statistical Manual for Mental Disorders, the DSM-5[29] is discussed in the Living Guideline Group's Supplementary Paper on the implications of the DSM-5 for the Guideline[19] (*see Appendix 3.5 for a summary*).

1.4 Formulation, disclosure of diagnosis and post-diagnosis support

Summary of recommendations

Recommendations and Good Practice Points:		Grade
1.4.1	Formulation, the process of integrating the assessment information systematically, 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, autistic characteristics, recommendations for supports, 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 autism/takiwātanga and support services should be available in a range of languages at all diagnostic disclosure interviews and through health and disability services (*see Appendix 3.8*).	B
1.4.7	Sources of post-diagnosis support should be identified for the person on the autism spectrum, and be culturally responsive (*see Appendix 3.8*).	C
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 autistic people 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.[84] 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[69] (*Recommendation 1.4.3*). The formulation should become a written report detailing the person's strengths and weaknesses, developmental course, autistic characteristics and recommendations for supports. It should also provide information on support networks[69, 73, 79] (*Recommendation 1.4.4*).

Whilst family-centred disclosure of diagnosis is recommended for autistic children, careful clinical judgement and attention to issues of privacy are required when disclosing a 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[112] (*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, understand what is being said, and opportunities to express concerns.[73, 113]

The 2018, Autism CRC published their 'National guideline for the assessment and diagnosis of Autism Spectrum Disorders in Australia'.[114] It suggests that when communicating the results of an autism assessment it include the following information:

- clear confirmation of the diagnostic outcome and a rationale for the diagnostic decision
- the diagnostic criteria utilised (e.g., DSM-5 or ICD-11)
- evidence that supports the presence or absence of each ASD diagnostic criterion
- evidence that supports the current severity level and specifiers (if DSM-5 criteria are utilised)[29]
- the assessments conducted, including the name of the instrument, what it measures, the administering professional, the findings and their implications
- co-occurring conditions identified, diagnosed, or requiring further investigation
- alternative conditions identified, diagnosed or requiring further investigation
- current developmental status/level of functioning across multiple domains and potential level of functioning with supports
- activity-related and character strengths
- environmental facilitators and barriers
- highest priority support needs and related goals
- suggested timeframe for a needs assessment to be repeated

- recommendations relating to further assessments if required, informal and formal supports required, and available funding and services.

In addition, in an Aotearoa New Zealand context, the cultural and language context of the whānau should be considered (*see Recommendations 1.4.6 and 1.4.7*).

People diagnosed with autism/takiwātanga and their families and whānau may raise issues that indicate a need for post-diagnostic support from an autism spectrum specialist or specially trained psychologist or psychiatrist.[73] This support needs to be culturally responsive (see *Recommendation 1.4.7, Good Practice Point 8.1, and Appendix 3.8 relating to the update on the impact of ethnicity undertaken through the Living Guideline process*[22]). Common themes include doubt about the diagnosis, depression and despair, anger, and fear.[113] However, some people find the diagnosis a relief, making sense of what has sometimes been years of difficulty.[61] Nevertheless, these people may also have significant issues.

Good post-diagnosis support helps the person to:

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

Part 2

Support for individuals, families and carers

“Ki a koe tētahi kīwai, ki a au tētahi kīwai o te kete”

For you one handle of the basket, for me the other

Part 2: Support for individuals, families and carers

Autism/takiwātanga has been described as a ‘hidden’ disability that affects every aspect of a person’s day-to-day life, including social inclusion. Some autistic people/tāngata whaitakiwātanga 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.[115] Studies have mostly focused on outcomes that are associated with the autistic person/tangata whaitakiwātanga. However, parents and whānau, partners, siblings, and carers are key people in the lives of the autistic person, 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. Autistic people/tāngata whaitakiwātanga also need support to improve their health and wellbeing.

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

2.1 Relationships

Summary of recommendations

Recommendations and Good Practice Points:		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	Alongside the stress of autistic children, the stress experienced by families and whānau 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 supports should always take into account both family/whānau and child variables and outcomes.	B
2.1.7	Autism-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 autistic people and the needs of autistic parents.	C
2.1.9	The perspective of grandparents should be researched to investigate the value of involving grandparents as part of the assessment process and to describe 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 an autistic child 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.[116] Factors associated with parent and family psychological distress include low levels of support from within the family and bringing up a child with 'behaviours of concern'[117] Difficulties increase in a context of societal expectations around children's behaviour, lack of day to day assistance, and lack of access to respite.

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.[118]

Most of the literature describes parents' experiences of helping an autistic person/tangata whaitakiwātanga to develop skills and enjoy activities as hard work and time-consuming, and the additional demands of caring for an autistic family member often continue into adulthood. Combining this with bringing up other children poses challenges in meeting the needs of the whole family.[57, 73] These challenges are more complex if families have more than one family member on the spectrum.[119] The behaviour of the autistic person will impact 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.[118, 119]

Longitudinal research on the experiences of parents and families as they adapt to the changing needs of an autistic family member is scarce, particularly with respect to autistic parents.[120-122] Research tends to concentrate on mothers and has a focus on the negative aspects of autism/takiwātanga, with limited research on cultural influences.

Research shows the economic and social impact of caring for family members with disabilities.[57, 123-125] Combined with costs of therapies and medication, supports and other services as well as lost earnings, the financial implications for a family can be significant. 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.[123]

Support and respite to minimise stress

Timely and more effective early support for autistic children may reduce the need for full-time 24-hour out-of-home placements for some young children on the autism spectrum.[14] Providing support to families who care for an autistic child may result in a significant cost-benefit to the government, saving expensive crisis management and providing quality of life to autistic people/tāngata whaitakiwātanga and their families[126] (*Recommendations 2.1.1 and 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.[125-127]

The value of parent-led support networks has also been identified.[128] 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[127] (*Recommendation 2.1.3*).

The strongest evidence for reducing stress in mothers identified the success of more structured supports, such as cognitive behavioural approaches. 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.[128]

Parent–professional collaboration

The evidence is clear that regardless of the support programme, 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.[118]

Parents have to take on multiple roles when their child is autistic. 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 or advocate, and this should be respected. When planning support programmes, 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.[14, 129, 130]

Eco-cultural theories hold that family values are embedded in daily routines and families and whānau maintain these routines to adapt to their environment. Research suggests that support programmes need to accommodate these routines or they will not be sustainable.[131] 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.[118]

Collaboration is associated with effective outcomes. A collaborative support programme considers that the child's and family/whānau characteristics (values, culture and resources) are important in designing supports and routines. A review of parent roles reported greater improvements for children following a collaborative-consultation model than with a teacher-only model[131] Information collected about the child from the parents and family/whānau, together with reasonable accommodations under the UNCRPD,[31] should be incorporated in the planning of the child's education programme (*Recommendation 2.1.4*).

Family participation should be 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[118] (*Recommendation 2.1.5*).

Support for Aotearoa 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,[14] include:

- easy access for families to information and support relating to their needs
- immediate appointment of a key worker who has autism expertise for coordination of supports for the child and family, with an outline of agreed time scales and dates (this person is not the same as the autism 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 autism/takiwātanga. Virtually all parents of children with learning support needs require support, partnership and substantial new skills and knowledge learned in the context of the needs of their particular child. Family and whānau knowledge, beliefs, aspirations, values, culture, and preference for services must be recognised and used for planning and provision of supports and services[14, 132] (*Recommendations 2.1.5 and 2.1.6*).

Observational research acknowledges the important role that parents have in any intervention/support 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.[133]

Staff working with a child should liaise closely to develop an individual plan and a family care plan, that include clear goals and strategies and are updated regularly. Family care plans should be written in a clear format and, where necessary, intensive autism service coordination should be provided to assist in accessing services.[14]

Advocacy

It is important to make information available to parents for their advocacy role in their children's education.[118]

Specialists and teachers can support parents to master an understanding of the vocabulary and systems of education, the characteristics of autism/takiwātanga, how those are related to a child's educational needs and gain an appreciation of how supportive 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.[118]

Education in advocacy skills should be available for parents and autistic individuals (*see also Part 4, 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[118] (*Recommendation 2.1.7*).

Rural issues

Equity is an ongoing issue for most autistic families. Rural families and whānau experience significant challenges and disadvantages in accessing resources and services (e.g., transportation, lack of local support and services, isolation, financial resources, lack of employment opportunities) compared with urban dwellers. Distance education programmes may be one way to make information accessible. Literature about the 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 'behaviours of concern' (one based on written materials with weekly telephone contact and one delivered through television).[131]

Cultural issues

Cultural differences need to be recognised and appropriately acknowledged. If teachers and other professionals do not understand what the child's autism/takiwātanga 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 autistic children. 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.[14, 130]

In Aotearoa New Zealand, it has been suggested that people working with Māori learners with learning support 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.[134]

A qualitative study that examined Māori perspectives of takiwātanga identified that, although parents' experiences of diagnosis were variable, many parents were well informed.[129] Most had encountered both helpful services and services with barriers. The report identified several areas of concern that highlighted the need for education in takiwātanga. Parents had a wide range of views concerning 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 takiwātanga).

Cultural issues raise barriers to parent education in Aotearoa New Zealand. As well as language barriers, there is late diagnosis, difficulties in attending programmes due to work and family commitments, and a need for a more community-focused approach.[135] Further information on Māori and Pacific Peoples' perspectives of takiwātanga is included in Parts 7 and 8.

2.1.b Siblings

There are special demands placed on the siblings who live with autistic family members. 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.[136]

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 autistic children experience their own stress and often bear more responsibilities than children with non-autistic siblings, a disabled sibling does not necessarily lead to a problematic sibling relationship. Positive sibling relationships are enhanced by the siblings having knowledge of autism/takiwātanga and through support programmes for siblings that are provided by support groups for children with similar conditions. Longitudinal studies should investigate changing relationships and the support needs of the non-disabled sibling.[137-140]

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 programmes, techniques, therapies and supports are identified for their disabled sibling and these needs should become part of a care plan.[14]

The personal needs of siblings mustn’t be overlooked. They should have an opportunity to learn about autism/takiwātanga and to have access to sibling support groups[137, 140] 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.[116] Siblings who attend the same school as their autistic sibling/s also need support in situations where they might be asked for help by teaching staff, or where they are teased about, by staff or peers, or embarrassed by their sibling's behaviour.

It is important to remember that the needs of siblings will change over time.[14] There is a lack of evidence on the effects of a diagnosis of autism 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 autistic sibling,[138] and to determine what types of information might be effective for siblings of different ages.[141]

Information about autism/takiwātanga 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.[142] This suggests that there is a potential for children and adolescents to receive multidimensional social support from online chat groups.

Siblings are more likely to show signs of autism than the general population. Younger siblings, particularly, require close monitoring to ensure that if they have indicators, supports can begin very early.[118]

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 any 'behaviours of concern' of autistic children. Grandparents themselves may have indicators of autism and/or struggle to adjust the thinking they grew up with. Community awareness and understanding of autism/takiwātanga are important to overcoming these barriers.[129]

Three key themes were identified from a qualitative study on the experiences of six grandparents of autistic children: the parental bond with the grandchild and adult child, striving for answers (the search for meaning) and the role of grandparents in holding the family together.[143] Their role in helping to inform clinical assessment work is unclear. The perspective of grandparents should be researched to investigate the value of involving grandparents as part of the assessment process and to describe the importance of their role in their ongoing support of family/whānau (*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 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.[144] Anecdotally, it is known that some grandparents may have looked forward to retirement after parenting their autistic child(ren), find themselves caring for their grandchildren who have been diagnosed with autism. Whatever the circumstances, information, support and services are essential to help grandparents to cope. An Aotearoa New Zealand handbook for grandparents and other carers exists which is a comprehensive resource – including further references and contacts for agencies – for grandparents who find themselves in this situation.[144]

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 autism-specific evidence in this area and further research into their support needs is recommended.

2.1.e Spouses and life partners

Autistic people/tāngata whaitakiwātanga do have intimate relationships, inclusive of marriage, life partnerships and homosexual relationships, although it should be noted that not all autistic adults will want or attain a long-term relationship. Although this is an area that remains under-researched, personal accounts by both partners and autistic individuals can be found in the literature[61, 145] including perspectives provided by counsellors.[146]

Challenges to these relationships include difficulties that are directly related to autism, particularly in relation to communication, socialising and imaginative thought. How a partner approaches and copes with the many difficulties that being autistic can present makes a difference to the coping mechanisms of both partners.[146] Appropriate support services are needed for autistic adults and their partners.

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

- learn about autism/takiwātanga 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 autism/takiwātanga
- 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 autism/takiwātanga offered to health and education professionals through their institutions include 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 autistic parents[73] (*Recommendation 6.4: Professional learning and development*).

2.1.f People raised by autistic parents

There is limited information on what it means to be parented by someone who is autistic.[147, 148] Very little research information was identified on the experiences of young children parented by autistic people/tāngata whaitakiwātanga (*Recommendation 2.1.8*). Several important child-welfare issues need to be addressed when the parenting threshold for an autistic parent has been exceeded, including the needs of children in custody arrangements, or following the death of a parent.

Several issues are raised in calling for further research to better support autistic people/tāngata whaitakiwātanga in their role as parents, including:

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

2.2 Parent information and education

Summary of recommendations

Recommendations:		Grade
2.2.1	Family members and whānau 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
2.2.2	All education services should be family/whānau-centred.	B
2.2.3	A key service to support families and whānau is the provision of information about autism/takiwātanga. 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

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 autistic children. 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 supportive approaches, techniques, programmes, and 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.[149]

A key service to support families is the provision of information about autism/takiwātanga. 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 autism/takiwātanga and the range of appropriate services and technologies[118] (*Recommendation 2.2.1*). The information needs to be accessible to everyone and includes 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.[73] 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 autism/takiwātanga and supports available
- guidance on mastering specific teaching strategies that enable them to help their child acquire new skills and behaviours
- information on understanding how autism/takiwātanga influences their child's learning and behaviour
- guidance on understanding their rights and responsibilities in the education system
- help in coping with the emotional stress that can follow from having a child with a significant developmental disorder.[131]

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.[118]

In a qualitative study of 19 Māori families and whānau in Aotearoa New Zealand, parents reported finding a range of information to be helpful: verbal explanations of takiwātanga at the point of diagnosis; a good talk with someone who knew about takiwātanga; 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.[129]

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.[150] 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 (e.g., access to transport, telephone, internet services).[151] 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 autism/takiwātanga (*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, teachers, and parents must 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 supports and professionals need to find sensitive ways to gather this information from parents and highlight its importance[118, 131] (*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 support methods for autistic children.[152] It has been noted that assessment of factors likely to influence the success and course of supportive approaches 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 approach 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.[153, 154]

Parent education is generally associated with improved family outcomes. Parent education increases the number of programme 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.[131] In addition, the use of effective teaching methods for autistic children 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.[118]

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.[131]

In summary, parent education should:

- be ongoing, for individual needs change according to the child's age and circumstances
- take a variety of forms (e.g., 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 (i.e., distance education)
- consider cultural issues such as differing perceptions of and approaches to disability and the impact of autism/takiwātanga on children's cultural development
- where possible, be available in the language of the participant's family
- include services for siblings and other family members.[14, 118, 129, 131]

2.3 Physical wellbeing

Summary of recommendations

Recommendations and Good Practice Points		Grade
2.3.1	Individualised support should be available to autistic people 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 autistic people should be developed and medical and health care practitioners trained in its use accordingly.	B
2.3.4	The health-assessment profile should include: • screening for mental health issues and the careful surveillance for emergence of 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.	B
2.3.5	Autistic people should have regular health checks, especially if they have an intellectual disability or have autistic traits that may affect their ability to self-monitor or report potential health problems.	B
2.3.6	Medical and health care practitioners should take into account the autistic traits of their autistic clients/patients and adapt their practices and procedures accordingly.	C
2.3.7	The dental needs of autistic people in Aotearoa New Zealand should be investigated.	B
	Autistic people should be provided with factual information on dental hygiene tailored to their cognitive level.	C
	Dentists should alter their processes and procedures to take into account the autistic traits of their patients.	B
2.3.8	The quality and quantity of sleep of autistic people should be considered by health care professionals and be addressed therapeutically.	B
	Medication and behavioural treatment of sleep disorders should be considered.	C
	The effectiveness of medication and behavioural treatment of sleep disorders should be further investigated.	C

Recommendations and Good Practice Points		Grade
2.3.9	Research should be undertaken to identify the needs of autistic people with regard to constipation, allergies, medication reactions, menstruation and exercise.	C
2.3.9a	Physical activities provide benefits across social, cognitive, and behavioural domains in addition to general wellbeing and should be considered for children and young people on the autism spectrum (*see Appendix 3.11*).	B
2.3.9b	When supporting individuals participating in a physical activity or programme, their preferences should be respected and needs accommodated (*see Appendix 3.11*).	✓
2.3.9c	Further research that targets meaningful outcomes for the Autistic community is essential (*see Appendix 3.11*).	✓
2.3.9d	Gastrointestinal problems, specifically constipation, chronic diarrhoea, altered bowel habits, and encopresis (faecal soiling), are more common in autistic children and young people compared with non-autistic peers (*see Appendix 3.4*).	B
2.3.9e	Autistic children and young people 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 (*see Appendix 3.4*).	C
2.3.10	In the absence of evidence for effective approaches to address specific health problems, help should be sought from suitably experienced health professionals.	C
2.3.11	All autistic children should be fully immunised including the MMR vaccine (Measles, Mumps and Rubella) in accordance with the Aotearoa New Zealand immunisation schedule. There is no scientific evidence to support the contention that this vaccine has a role in the causation of autism/takiwātanga.	A
2.3.12	The effectiveness of health-promotion campaigns with autistic people should be investigated. Health-promotion campaigns should ensure that autistic people 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 autistic people who also have an intellectual disability.	B
2.3.14	Sensory issues in autistic people should be identified and appropriately addressed by occupational therapists with experience in autism/takiwātanga. These assessments should lead to specific recommendations.	B

Recommendations and Good Practice Points	Grade
2.3.15 Methodologically rigorous research is needed to examine the effectiveness of current evaluation methods and approaches used to address sensory issues.	B

2.3.a Health needs

As described in Part 1 of the Guideline, the health care needs of autistic people/tāngata whaitakiwātanga can be complex. Not only do autistic people have a higher likelihood of epilepsy and other co-occurring conditions (*see Part 1, section 1.3: Differential diagnosis*), but also the appropriate management of their health care needs is complicated by the impact of the traits of autism/takiwātanga itself.

For example:

- the level of social skills development that autistic people/tāngata whaitakiwātanga 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 autistic people/tāngata whaitakiwātanga 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 autistic individuals 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 Aotearoa 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 be autistic 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 autistic adults access only GP care and do not access specialist services. Accounts by autistic people/tāngata whaitakiwātanga 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.[61, 155]

Some autistic people/tāngata whaitakiwātanga need support to manage their physical wellbeing appropriately, and medical and health care practitioners require knowledge of autism/ takiwātanga 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 autistic people/tāngata whaitakiwātanga[14]
- routine health care screening[156]

- 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 autism/takiwātanga should occur both in initial and in post-qualification training of GPs, nurses and other health care practitioners[156-158]
- educating families, whānau and carers on how to, first, support the autistic person to attend to their 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/support network to ensure that their needs are understood
- work within the interests and strengths of the autistic person
- alter agency procedures to take the autistic person's needs into account (e.g., have several short appointments rather than one long one depending on the autistic person's preference or capacity, use the same room each time, fit into their daily routines and use language they understand, allow extra time for processing or for a person using an AAC device)
- 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[61, 155, 158-160] (*Recommendation 2.3.6*).

2.3.b Specific health care issues

Acute and emergency care

Acute and emergency medical care presents special problems for autistic people/tāngata whaitakiwātanga 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. All health care staff and emergency responders must have education on the needs of people with disabilities, including autism/takiwātanga. Occasionally, sedation or even general anaesthesia may be required for procedures that could typically be carried out on fully conscious children or adults.

Dental hygiene and care

Some evidence exists suggesting that the oral hygiene of some autistic people/tāngata whaitakiwātanga is compromised and that autistic people have an increased risk of caries and periodontitis.[160] A preventative measure recommended in the literature sourced was providing information and explanations on good dental hygiene in a manner suited to autistic people.[160]

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
- access to specialist dental services may be essential where procedures require sedation or general anaesthetic to enable dental treatment and avoid more intrusive measures (after explanation and obtaining written consent)
- organisational changes to the office and appointment scheduling[159-161] (*Recommendation 2.3.7*).

Sleep disturbance

Research suggests that whilst sleeping difficulties are frequent in typically developing children, children and adults on the autism spectrum have significantly more sleep problems.[162, 163] In particular, autistic adults 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.[164] Research has indicated that autistic children exhibited the same range of sleep problems as their non-autistic peers (e.g., difficulty settling, night waking, early morning waking, and co-sleeping), but were more sluggish and disoriented after waking.[162] Treatment by medication or behavioural sleep management programmes or both has been assessed by research studies, but more research is needed[162, 163] (*Recommendation 2.3.8, see Part 4, section 4.4.a*). Note that research on the use of the hormone melatonin for autistic children and young people was updated as part of the Living Guideline process, and is summarised in Appendix 3.2, and available as full text from Whaikaha – Ministry of Disabled People's website.[16] This review concluded that melatonin can be recommended for use in autistic children and young people who are experiencing significant sleep problems, although longer-term treatment requires further investigation. Standard sleep hygiene procedures may be appropriate to use before medication and other approaches.

Other health issues

Physical activities provide benefits across social, cognitive and behavioural domains in addition to general wellbeing[165] and should be considered for children and young people on the autism spectrum (*Recommendation 2.3.9a, and Good Practice Point 2.3.9b*). Research on the effectiveness of physical activity programmes for young people on the spectrum was updated as part of the Living Guideline process. It is summarised in Appendix 3.11, and is available as full text from Whaikaha – Ministry of Disabled People's website.[25] It revealed consistent evidence that physical activity appears to show significant improvements in social functioning outcomes such as social interaction skills. Cognitive functioning and behavioural functioning measures are also improved in most studies evaluating outcomes in these domains. Although the existing evidence relates primarily to children and young people, it is likely to apply to adults.

Gastrointestinal problems, specifically constipation, chronic diarrhoea, altered bowel habits, and encopresis (faecal soiling), are more common in autistic children and young people compared with non-autistic peers. Autistic children and young people 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 (*Recommendations 2.3.9d and 2.3.9e*). Note that research on gastrointestinal issues in autistic children and young people was updated as part of the Living Guideline process[18], and is summarised in Appendix 3.4, and available as full text from Whaikaha – Ministry of Disabled People's website.

Issues identified in the literature, but about which no reliable research was found, include allergies, medication reactions, and menstruation.[166] There are examples in the literature of practical suggestions for the health care of autistic people/tāngata whaitakiwātanga and advice should also be sought from suitably experienced health professionals[167] (*Recommendations 2.3.9 and 2.3.10*).

2.3.c Immunisation for children who are autistic

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 disease is much less likely to contract that disease than a child who has not been immunised. Children who are autistic may not cope with illness as well as their non-disabled peers. In particular, autistic children (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 the 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 Aotearoa 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 the MMR vaccine (Measles, Mumps and Rubella). This vaccine is given at the age of 15 months in Aotearoa New Zealand.

In 1997, a group of workers studying gastrointestinal symptoms in children announced (at a press conference before the publication of their work) said that they had found a link between the development of autistic traits and the prior administration of the Measles, Mumps and Rubella (MMR) vaccine. Since then many large and well-conducted studies of whole populations have demonstrated definitely that this claim has no basis in fact, and the publication has since been retracted.[168] The lead author was subsequently found guilty of serious misconduct and struck off the Medical Register by the General Medical Council in the United Kingdom. He was 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.[169, 171] A 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.[172]

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 Aotearoa 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 autism (*Recommendation 2.3.11*).

2.3.d Nutrition

Full discussion of the nutritional issues in autistic children is outside the scope of the Guideline.

Some children who are autistic restrict their intake of food by refusing foods based on smell, taste, texture, and colour. Such children may be very sensitive to small changes in the food offered, such as changing the brand of, for example, bread. Children may also restrict their intake based on 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 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 iron, vitamins and trace elements) is inadequate.

In this situation, the child's nutritional state should be assessed by their general practitioner, paediatrician or 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, although these are unlikely to be useful as a 'treatment' for autism; see *Recommendation 4.5.1*). Parents should ensure that children on these diets also receive adequate intake of vitamins and trace elements, especially where the child also self-restricts the range of foods taken.

Resources for parents can provide some guidance on this issue.[173, 174]

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 that assessed the effectiveness of these campaigns for autistic people/tāngata whaitakiwātanga, given their communication, cognitive and social characteristics, it is likely that effectiveness is less than optimum. Adapting national health campaigns to more effectively engage autistic people and their families and whānau (e.g., through the use of visuals and web-based initiatives) and developing autism-specific campaigns on health issues has been recommended internationally[73, 156] (*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 autistic people/tāngata whaitakiwātanga who have an intellectual disability 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.[175, 176] Communication issues were linked with impaired assessment, diagnosis, ongoing care and the ability to fully inform patients.[176, 177] 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.[156, 176]

Recommendations made on the health of people with an intellectual disability are of high relevance to autistic people/tāngata whaitakiwātanga, many of whom 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 Aotearoa 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 Te Whatu Ora Health New Zealand 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*[176] *(Recommendation 2.3.13).*

2.3.g Sensory processing

Evidence confirms the existence of sensory and motor difficulties for many autistic children[118, 178] (*see also Part 3, section 3.2.c: Sensorimotor development*). Most of the research evidence on sensory processing difficulties is derived from studies on children and young autistic people/tāngata whaitakiwātanga but may be relevant to older autistic people 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 characteristics of which may have an impact on a person's ability to communicate and relate to others.[179]

Autistic people, their families and carers have observed disordered levels of sensitivity to visual, auditory, olfactory and tactile stimuli. Sensory challenges include a wide range of perceptual experiences and can cause atypical 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 on health and wellbeing. Assistance to put strategies into place can help people to succeed[180] (Recommendation 2.3.14). 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 intellectual disabilities
- tendency to obsess
- often anxious
- poor eating habits
- passive or aggressive behaviours
- developmental regression.

Autistic-like traits common in blind children (but which also occur in non-autistic blind children) include room hugging, spinning themselves and spinning objects, self-stimulation, and echolalia.[56] Some blind children fit the diagnostic criteria for ASD,[181] with evidence suggesting autism is more common in congenitally blind children than in the typically developing population,[182] and can be identified using standardised ASD assessment tools, such as the Childhood Autism Rating Scale.[183] The literature suggests that teachers, family, whānau and carers of visually impaired autistic people/tāngata whaitakiwātanga 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 characteristics of each condition clearly, rather than simplistically attributing behavioural or emotional issues to other causes (e.g., poor parenting skills, impaired mother-child attachment).[56, 184]

Behavioural similarities also exist between deafness and autism, to the extent that hearing impairment is often suspected in children eventually diagnosed with ASD. However, some autistic people/tāngata whaitakiwātanga are hearing-impaired or deaf as well,[185, 186] and ear infections occurred commonly in a sample of 190 children and adolescents with autism.[186] The DSM-IV[30] criteria and the Autism Screening Instrument have been used to diagnose ASD in deaf children.[185, 186] Issues for the support of hearing impaired and deaf autistic people/tāngata whaitakiwātanga are the same as those above for blind people.

Assessments

Atypical responses to sensory stimuli are so common that they are seen by many as cardinal traits of autism despite not being recognised in the DSM IV.[152] Sensory processing difficulties may explain some autistic behaviours and differences in cognitive processes may explain others[187] 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 the community.[188, 189]

Assessments and supports should be delivered by therapists with appropriate experience.[188] 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 the autism spectrum and the assessment should lead to specific recommendations[14] (*Recommendation 2.3.14*).

Supports

There is no consistent evidence that sensory-based approaches have special effects (*see also Part 3, section 3.2.c: Sensorimotor development*).[190] 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 techniques and approaches being used by occupational therapists (*Recommendation 2.3.15*).

Special forms of occupational therapy are used to help autistic people/tāngata whaitakiwātanga to overcome their isolation, progress developmentally, find ways of coping and gain a sense of self and relatedness to the world.

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 Part 4, section 4.5: Other approaches*).

2.4 Coordination of services

Summary of recommendations

Recommendations and Good Practice Points:		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 the planning and implementation of service provision.	C
2.4.4	A coordinated approach to planning and implementing services should be developed to meet the identified needs of an autistic individual, 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 autistic children experience tend to change over time.[129, 131] 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 makes their child different developmentally or to have 'behaviours of concern
- 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, the Child Disability Allowance (CDA), and advice about education and behaviour.[191-193]

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

- have information on autism and how it affects the person
- receive timely practical assistance, including preventative services and supports to minimise the need for crisis management
- have information on support services, autism 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 (though ideally they shouldn't need to)
- 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 approaches, substitute care and transition services to adulthood[194] (*Recommendation 2.4.2*). Families of younger children especially need access to services and supports during school holidays such as school holiday programmes.[14]

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.[195]

Many of the issues faced by carers are not inherent to the characteristics of the autistic person but are socially constructed.[196] Researchers advocate:

- easily accessible 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.[196]

Service coordination

The need for service coordination and case management for autistic individuals is emphasised throughout the Guideline (*Good Practice Point 2.4.4*). The heterogeneity of the condition of autism (wide range of expression of characteristics, age at diagnosis, intellectual ability, communication abilities and preferences, 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 access Government-funded disability support services. See: www.supportoptions.co.nz.

The Health Funding Authority (an earlier funding body whose functions are now fulfilled by the Ministry of Health and Te Whatu Ora Health New Zealand) developed guidelines for needs assessment and services coordination agencies working with autistic people supported by their families/whānau.[197] The Health Funding Authority Guidelines recognise that the nature of the needs of autistic people/ tāngata whaitakiwātanga 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 autistic people.

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

- the autism 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

Education for learners

“Poipoia te kakano kia puawai”

Nurture the seed and it will blossom

Part 3: Education for learners

This part of the Guideline deals with the range of assessments and supports for autistic children and young people 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 to the various domains of learning. Further information and guidance are provided in Appendix 7. Educational programmes that incorporate some of the outlined principles are listed in Appendix 8.

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 Aotearoa 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 autistic children. Models should be chosen to fit the characteristics of the child and the learning situation.	B
3.1.3	Decisions about the type of support 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 i.e., with their usual carers and teachers and with access to peers who are not autistic.	B
3.1.5	Support programmes 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 support 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 supports 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 support plans.	C
3.1.11	A child's educational programme should reflect their interests and culture, and the developmentally appropriate learning models for their age (*see Appendix 3.8*).	C

Good Practice Points:		
3.1.12	Specialist early intervention staff should provide education and support to families, whānau and early childhood teachers on how to provide structure and supports for children in their natural settings i.e., 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 support

There is a growing body of evidence that good quality early support results in positive outcomes for autistic children[118, 198-202] (*Recommendation 3.1.1*). There is some evidence that children who participate in intensive support programmes before the age of three have a significantly better outcome than those beginning after five years of age.[118, 202]

Research into supports for young autistic children requires the overcoming of many challenges.[89, 118, 200] These include matching sample groups in such a heterogeneous population and controlling for a wide variety of other variables (e.g., parents using other therapies or supports outside the study programme and finding adequate instruments to measure progress). Many factors make it difficult to compare and/or replicate results. For example, studies use different outcome measures to demonstrate progress (e.g., IQ, school placement, adaptive behaviour or functional spontaneous language and generalisation).[118] Many of the published studies of early intervention programmes are from university model programmes of early intensive approaches. 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.[118] These characteristics provide a challenge in considering research findings for Aotearoa New Zealand practice where resources are scarcer and supports tend 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 autistic children that have been reported in the literature. Apart from education programmes, other supportive approaches 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 supportive approaches*). It has been suggested that most educationally based support 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.[203] 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[204, 205]
- approaches that draw on behavioural and developmental research, for example, Pivotal Response Training[206] and SCERTS™[207]

- developmental (social pragmatic) approaches, for example, ‘Floortime’.[208, 209]

The approaches represent a continuum of different philosophies and outcomes. They differ on several 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 non-autistic peers.[204]

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 autism’ 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.

Discrete trial training

Applied behaviour analysis (ABA) is a branch of behavioural psychology that, 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.[210] 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.[201]

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 are most concerned with specific programmes which use traditional DTT methods, such as the Lovaas’ intensive behavioural therapy[204] and other programmes that use similar principles. The controversy initially focused on several issues, including (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 autistic children.[211]
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 to 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.[211]

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 conflicts with evidence that supports and strategies for autistic individuals must be tailored and cannot be used as a 'one size fits all'. The most appropriate and efficacious programmes for autistic children employ a variety of practices, including systematic and ongoing evaluation.[14, 118, 203, 212]

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 supports 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.[118, 203, 210, 212, 213]

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.[203]

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.[212]

Concerns around ABA: Updated commentary for the third edition

Since the Supplementary Paper on Applied Behaviour Analysis (ABA) was published in 2010[15] (*see Appendix 3.1*), the Living Guideline Group (LGG) have not identified ABA as a topic meeting criteria for update in its annual prioritisation process. That is, in their judgement a review of new evidence is unlikely to lead to a significant revision of the existing recommendations that ABA (*Recommendation 4.3.5a*) and Early Intensive Behavioural Interventions (EIBI) (*Recommendation 4.3.5b*) "be considered" for autistic children.

Over the years since the publication of the Supplementary Paper on ABA[15], the LGG have become aware of concerns raised around potential harms from ABA therapy, including preliminary evidence of delayed trauma,[214] potential risks of masking[215] and forced compliance[216] impacting long-term mental health, and broader ethical concerns.[217] Debates continue around this evidence, what constitutes ABA, goals of therapy, targeted behaviours,[218] and best practice.[219] This topic will be considered for update as new evidence becomes available, particularly concerning potential long-term impacts and harms.

It should be noted that concerns around ABA may not apply to all its forms or applications. Many therapies and strategies are based on behaviour theory (behaviourism), including a group of 'behavioural' approaches loosely described as ABA. These include Early Intensive Behavioural Interventions (EIBI), Discrete Trial Training (DTT), Positive Behaviour Support (PBS), and the Picture Exchange Communications System (PECS). More recently, another class of supports has emerged based on both behavioural principles and developmental theories of learning. These Naturalistic Developmental Behavioural Interventions (NDBI) include the Early Start Denver Model (ESDM);[220] Enhanced Milieu Teaching (EMT);[221] Pivotal Response Treatment (PRT);[206] and Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER) (among others).[222] NDBI have been considered a separate supportive approach to ABA.[223] However as these supports can be understood as based on the principles of behaviour theory, they are all relevant to the evidence supporting *Recommendation 4.3.5a*, and *Good Practice Points 4.3.11 and 4.3.12*.

The LGG qualified their advice supporting the use of EIBI (Recommendation 4.3.5b) by noting there was "substantial individual variability in outcomes, ranging from very positive improvements, through minor or minimal improvements, to no effects".[15] It was also observed that there was uncertainty about the optimal intensity of hours, and for whom EIBI benefits. The LGG also noted the lack of knowledge about the suitability of EIBI for the diverse ethnic and cultural groups of Aotearoa New Zealand (*see Appendix 3.1*).

Lastly, readers are reminded that the Guideline does not advocate for one approach or model over another (*see Recommendation 3.1.2*). The most effective programmes employ a variety of strategies and approaches, and include a systematic and ongoing evaluation of progress.

Readers are referred to new Good Practice Point 4.3.13 which offers guidance for individuals and whānau in choosing a supportive approach, strategy, practitioner or therapist to ensure principles for ethical practice are followed. Conflict of practice, goals, or promises with these principles should represent 'red flags' and we would advise consumers look elsewhere for support.

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.[224] 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.[203]

Researchers have identified several 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.[203]

(For a further description of the programmes mentioned in this section see Appendix 8: Educational approaches.)

3.1.c Implications for practice

Which is the best supportive approach?

No one model has been shown to meet the needs of all autistic children.[118, 201, 203, 210, 225] 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.[198, 202, 203] The most appropriate and efficacious programmes for autistic children employ a variety of practices, including a systematic and ongoing evaluation of supports[14, 203, 212] (*Recommendation 3.1.2*).

Young autistic children 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.[212, 213]

What is known about the characteristics of quality support programmes?

A number of characteristics of successful programmes have been identified.[118, 199, 213]

1. **Making the earliest possible start to support**

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.[118, 199, 213] 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[118, 199, 202, 213] (*Recommendation 3.1.1*).

2. Individualising services for children and families and whānau

Individual plans should be developed for autistic children who are identified as having specific support needs.[199] 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 (*Good Practice Point 3.1.12*).[213]

Research suggests that it is important that such individualisation incorporate the child's interests and motivations as well as developmental needs.[118] Developing and maintaining an individual profile for the child can help with this.[14, 203]

Services and supports should also match the needs, priorities, concerns and interests of families.[199, 202, 213] Professionals' knowledge of the family's current goals should be updated regularly [213] (*Recommendation 3.1.3*).

3. Providing systematic 'planful' teaching

Systematic goal-directed teaching needs to be carefully planned and has a strong conceptual base.[199, 213] Optimal strategies may be different depending on whether a new skill is being taught or an existing behaviour generalised.[89] Those working with children need to be familiar with a range of supports and in what circumstances they can be used appropriately.[200, 210, 226]

While adequate individual instruction is crucial to early learning, the greatest effect for autistic children 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[118, 203, 210] (*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.[89, 203, 213]

An important aspect of systematic teaching is ongoing evaluation and assessment.[118, 201, 213] 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.[203] There are many assessment tools and techniques. Learning Stories,[227] which is a narrative-based form of assessment and currently widely used in Aotearoa New Zealand early childhood education services, maybe one useful technique to document these developments. However, for this to be useful for autistic children, the observer needs to have a good working knowledge of the autism spectrum and how it affects the particular child being observed.[227] Whenever possible, observations and assessment are most effectively conducted in the child's natural environment.[203, 228]

If a lack of progress towards goals is seen over three months, 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 support goals or providing extra consultation and support to staff[118, 213] (*Recommendation 3.1.5*).

All staff must have appropriate education and qualifications in supporting autistic children and have professional learning and development, opportunities and time to develop the skills and knowledge that early intervention teams need to be effective[14, 89, 118, 213] (*Recommendation 6.18: Professional learning and development*).

4. Providing a curriculum to meet the needs of the young autistic child

Priority should be given to goals that emphasise functional spontaneous communication and social development, including play[118, 199, 201-203, 210, 213] (*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.[118, 199, 203] Provision of proactive supports for addressing behaviour challenges, which usually involve teaching the child alternative skills and making environmental and learning adaptations, is another high priority.[118, 213]

There is evidence that addressing 'pivotal' areas will have the greatest probability of positive effects in many areas of functioning.[89, 201, 202] Pivotal skills training[206] addresses teaching core areas of functioning such as improving motivation, responding to multiple cues, self-management and self-initiation of social interactions. This conflicts with the notion of targeting many individuals or narrowly defined behaviours[201] (*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 (where an inclusive setting is provided with appropriate accommodations and adjustments)
- 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.[229]

5. Intensity of engagement of the autistic child

Supports for the young autistic child (i.e., those below eight years) require intensity, but the optimal amount of intensity for different children is still not determined.[202] Hours of intensive support programmes do not necessarily equate to effective practice or improved outcomes. The quality of the support/education is at least as important as its intensity.[201] The intensity of support 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, as well as time with other professionals (such as speech and language therapist and occupational therapists).

For non-autistic children, providing an opportunity to participate in a developmentally appropriate activity is sufficient to have an educational benefit. For autistic children, 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,[89, 199] although there is considerable debate about how engagement is defined.[14, 89, 118, 199, 200, 203]

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.[118] 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
- specific activities, 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 autistic children to make progress, they need to be engaged in developmentally appropriate activities or interactions for at least 15 to 25 hours a week[14, 118, 199, 229] (*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.[89, 118] 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.[118]

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 supports and evaluation should consider not just child but also family/whānau variables and outcomes[89, 203, 210] (*Recommendation 3.1.9*).

Family-centred services are already a well-recognised and important part of Aotearoa 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.[199, 210, 213, 226]

Families and whānau need to be part of the team involved in the development of priority goals and support plans (*Recommendation 3.1.10*). The family’s perception that the goals chosen are socially valid is of the utmost importance.[226] If they wish, they should receive support and training so that they can incorporate the generalisation of skills into daily routines.[118, 199, 202, 210]

7. Structured environments

A structured environment for young autistic children is strongly recommended.[118, 199, 203] 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 autistic children. Teachers need education on how to provide structure within these environments (e.g., 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.[118, 213]

A careful balance is required between highly structured environments and autistic children learning to adapt or cope with change.

8. Developmentally appropriate practices

Although autistic children 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.[118, 199, 200, 210] For the very young child, this often means learning through play and following their interests and culture (*Recommendation 3.1.11*). Developmentally appropriate practice is an important tenet both in research and in Aotearoa New Zealand early childhood education services. Te Whāriki emphasises this point.[230]

9. Supports in natural environments and with access to non-autistic children

Best practice for autistic children is not achieved by teaching in isolated settings away from other children and the quality of a supportive approach is at least as important as its duration.[118, 199, 203] Inclusion of children on the autism spectrum in regular settings is a common early childhood education practice in Aotearoa New Zealand, but the lack of structure and high noise levels in these settings may make it difficult for some young autistic children 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.[199, 203, 228]

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

Aotearoa New Zealand is fortunate and unique in having an early childhood education curriculum. Te Whāriki (the Aotearoa 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 autistic child 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 (e.g., home to early childhood education centre), changing activities (e.g., meal time to bath time) and when changing to a new education setting (e.g., beginning school). These transitions require careful planning for both the child and the new environment.[229]

A key transition is to move from home to an early childhood education setting and from there to school. A survey has identified several successful programmes for young autistic children. 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 that take place on a gradual basis
- using social stories[231] and other visual strategies to introduce the new setting and the people in it[116, 229, 232] (*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 several different areas of the curriculum for autistic children and young people in educational settings and how they influence learning. It covers communication and literacy skills, social development, sensorimotor development, cognitive skills, and self-management skills.

3.2.a Communication and literacy skills

Summary of recommendations

Recommendations and Good Practice Points:		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 autistic children and young people.	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 supports.	C
3.2.1.4	Supports 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
3.2.1.5a	When assessing immigrants and others where English is not their first language, it is important that interpreters and translators are available (*see Appendix 3.8*).	✓
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	Timely access to 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 focused interests.	B
3.2.1.10	All autistic children should have an assessment and support suggestions by a speech-language therapist with expertise in the autism spectrum at a minimum of once a year, more often in early childhood.	✓
3.2.1.10a	Supports should be culturally responsive for the child or young person (*see Appendix 3.8*).	✓

Background

Communication is one of the most well-researched areas of the autism spectrum.[118] However, most of the research and evidence related 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 autistic child.[202]

Communication is a core difficulty for all autistic children, but there is a wide diversity of skills among individuals. Impacts can range from a failure to develop any functional communication at all to the development of apparently good language, but with unusual elements.[118, 202]

While research studies report that between one-third and one-half of children diagnosed with ‘classic autism’ do not develop functional language, this may not reflect the effectiveness of current supports.[118] The use of spontaneous communicative speech in autistic children before the age of five indicates a good prognosis for IQ, language, adaptive skills, and academic achievement in adolescence.[118, 202] Development of communication skills is also closely correlated with the development of social behaviour.[202]

Communication is a complex process and has several different aspects.

1. **Receptive communication**

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

- difficulties with auditory processing – receiving and making sense of auditory information
- difficulties with comprehension, including:
  - difficulties attaching meaning to words
  - lack of prior experience, context or knowledge
  - affected 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 a 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 autistic children.[89, 118]

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.[89, 118]

4. Symbol use

This involves learning to use conventional gestures and understanding and using the conventional meaning of words. It also includes learning to use objects functionally and in symbolic play. Autistic children often find these skills difficult, but an understanding of symbol use is regarded as an important basis for communication.[118, 202] Many autistic children find visual quasi-symbols, such as photos and pictograms which are more static, easier to comprehend than verbal language.[118, 233]

5. Social pragmatic skills

Communication supports 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.[118] Children and young people who develop fluent speech may still have difficulty with social rules governing conversation.[118] Difficulties with prosody, which includes rate, rhythm, inflection and volume, also provide challenges that need to be addressed.[234]

6. Echolalia

Autistic children who learn to talk often use echolalia as they start to communicate.[118] Echolalia can be immediate (i.e., an echo of something just spoken) or delayed (i.e., 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.[235] Many children eventually learn to break these scripts down into smaller, more meaningful chunks.[202] Even after children have developed more fluent speech, echolalia may reappear when the child is confused or fatigued.[235]

7. Unconventional behaviours

Children who do not develop fluent communication skills may use inappropriate or unconventional behaviours such as aggression or self-injury as means of communication. When autistic individuals are supported to develop/improve communication skills, and/or access to appropriate augmentative and alternative communication (AAC), they are more able to express their needs in helpful ways.[118] 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 'behaviours of concern'. This approach has the advantage of teaching the individual to communicate, as well as reducing undesirable behaviours[118, 202, 203, 233] (*this is discussed in more detail in section 3.2.e: Self-management skills and addressing 'behaviours of concern'*).

Approaches to supports

In the 1970s and 1980s, the developmental pragmatic literature which looked at the development of communication for social purposes began to influence supports for autistic children.[203]

Speech is only one form of communication, but in the past, it has been seen as the main focus for support programmes for autistic children.[89] 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.[203]

Most children understand a lot about communicating before they learn to speak and it is equally important for autistic children to develop this pre-verbal knowledge. Very young non-autistic children begin to communicate using informal means such as gestures – for example, raising their arms to be picked up, or pointing. Young autistic children 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.[235]

Implications for professional practice

The research strongly indicates that improving communication is a very high priority for autistic children.[14] The assessment and development of communication and social goals should complement each other. Teaching of the two areas should be carried out in parallel[118, 203] (*Recommendations 3.2.1.1 and 3.2.1.2*).

One study reports success in teaching young children joint attention skills and symbolic play which generalised to playing with caregivers.[222]

There is increasing evidence for the importance of encouraging initiation and spontaneous communication[202] (*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.[118, 202]

The research increasingly emphasises the importance of supports that 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.[89, 118, 202] 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 an approach (*Recommendation 6.6: Professional learning and development*).

Supports which emphasise the capacity to understand the purpose of communication rather than simply focusing on the form of the message (e.g., learning to use words) are most important.[89, 118] Children who learn speech and language, or communicate through AAC, 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.[202, 203]

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.[235]

Formal measures should always be supplemented by informal assessments which include observations across a variety of settings and activities, and interviews with significant adults[14] (*Recommendation 3.2.1.5*). Aspects that need to be assessed include eye gaze, facial expression, the child's range of communicative functions and use of gestures.[118] When assessing immigrants and others where English is not their first language interpreters and translators must be available (*Good Practice Point 3.2.1.5a*). Also allow for cultural differences when assessing areas such as eye gaze.

The most effective communication assessments are those performed by members of a multidisciplinary team in conjunction with assessments of other aspects of development.[14] 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[14, 118] (*Recommendation 3.2.1.6*).

For older children and young people with less obvious support needs, 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[236] (*Recommendation 3.2.1.7*). It is also important to consider their ability to engage in conversation and repair breakdowns in communication.[118]

Outcome measures

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

- the initiation of spontaneous communication

  The emphasis should move from simply measuring the ability to say or use words to considering 'spontaneous communication' (i.e., the ability to send a message to another person). Many autistic children tend 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 that 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

  Autistic children and young people 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 supportive approaches is increasing competence in the natural settings associated with the child's life.[89, 118, 202, 203]

Teaching strategies

1. Use of augmentative communication

There is a considerable body of evidence to support the use of augmentative communication strategies with autistic children and young people.[14, 118, 232, 237, 238] These strategies are used to support existing speech or as part of a multimodal system of communication which may include gestures.[233]

Augmentative communication supports tend to suit the distinctive strengths and needs of autistic children. 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.[233]

The rationale for their use includes the:

- strong visual processing of many autistic children
- predictable and static nature of visual information
- close and obvious relationship of the picture to the concept it represents
- role such supports may play in assisting children to rely on visual or symbol recognition to understand rather than relying simply on memory recall.[118]

Research suggests that aided symbol use (such as photographs, line drawings, symbols or written words) may enhance the development of speech in autistic individuals. 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.[118] 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 other settings.[239, 240]

Using manual signs as augmentative communication is 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.[118, 233]

It is important to make a careful selection from the many resources available for the most appropriate support or device. Like all approaches to this population, careful assessment and planning are 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.[233]

Evaluation of the effectiveness of any resource needs to be done in a natural setting to ensure that its use has been generalised.[237] Use of visual supports and technology can effectively assist with this goal by supporting the 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[118] (*Recommendation 3.2.1.8*).

2. Computers

While there is little research on specific computer programmes for autistic individuals, there is some evidence that computer technology may enhance motivation, increase attention, and reduce 'behaviours of concern' in individuals across the ability range.[233] Computer-based schemes are seen as particularly valuable for literacy development.[232, 241]

3. Literacy skills

In the past, despite demonstrating skills directly related to literacy, some autistic children have been labelled as too cognitively 'impaired' or not ready for literacy instruction.[238] There is evidence of situations where individuals 'without speech' have learnt to read and write.[238, 242] 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 focused interest, at least until the interest wanes and drifts into another.[238]

Some autistic children have hyperlexia, which is being able to read words beyond what would be predicted based on 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 autistic people/tāngata whaitakiwātanga 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. Autistic children are capable of learning to understand what they read, but it should not be assumed that they can comprehend all the words they can decode. Hyperlexia occurs in children with a wide range of disabilities, but disproportionately in autistic children (up to 10%).[233, 238]

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[238] (*Recommendation 3.2.1.9*).

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

- some children on the autism spectrum can sight-read words without teacher-directed rote drill
- supports that use recommended practices for children without disabilities are also useful for autistic children
- literacy-rich early childhood education service environments can promote literacy learning.

The recommended support is a balanced one that incorporates all the processes that are known to be involved in successful literacy learning.[233]

3.2.b Social development

Summary of recommendations

Recommendations and Good Practice Points:		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 supports should take place in natural settings and within natural activities as much as possible.	A
3.2.2.4	Supports using carefully trained and supported non-autistic peers should be encouraged.	A
3.2.2.5	All social support 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 supports in the home.	C
3.2.2.6a	Tailored sexuality education, particularly when delivered individually and intensively, should be considered for young people on the autism spectrum (*see Appendix 3.9*).	B
3.2.2.7	Socialisation goals should be included in all individual education plans.	✓
3.2.2.7a	All those who support young people and adults on the autism spectrum should be sensitive to gender and sexual diversity.	✓
3.2.2.7b	Sexuality education programmes in Aotearoa New Zealand need to be responsive to the cultural and linguistic diversity of their participants (*see Appendix 3.9*).	✓
3.2.2.7c	Aotearoa New Zealand research is needed to develop and evaluate sexuality education programmes for young people on the autism spectrum (*see Appendix 3.9*).	✓
3.2.2.7d	Decisions about participating in sexuality education should be guided by whether a person on the autism spectrum values it, and whether they are expected to benefit from it (*see Appendix 3.9*).	✓

Background

Social difficulties are one of the core affected areas for autistic children.[118, 228, 243-245] Social challenges may appear in the first few months of life.[228] One of the earliest signs is a lack of typical response to physical contact.[243] Studies show, however, that autistic children tend to have standard attachment patterns with their parents or carers.[118]

The social interactions of autistic children 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.[118] This difficulty is most marked in interactions to share experiences and establish a joint focus of attention, rather than in initiations to have needs met and continue pleasurable experiences.[118]

Autistic children 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.[228, 243] They pay less attention to other people's emotions and tend to demonstrate fewer acts of empathy or shared emotion than do children who are not autistic.[118] Note however that the 'double empathy' theory suggests that autistic people/tāngata whaitakiwātanga do not lack empathy but that they experience the world and express emotions differently to non-autistic people. Autist people/tāngata whaitakiwātanga may have difficulties around, or lack 'social insight' into, the culture and communication of non-autistics. This disconnect has been called a 'double problem' because both autistic and non-autistic people experience a lack of understanding of the other group.[246]

As the nature of communication challenges has been more accurately researched, it has become easy to see that social competence is closely related to impacts on verbal and non-verbal communication.[243]

Research has identified subgroupings of children based on 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, has intense focused interests and lacks understanding of others) and 'over formal and stilted' (excessive formality and difficulties with the subtleties of social situations).[118] These groupings can be useful to help focus supportive approaches and set priorities.

Difficulties with speech and/or alternative communication systems do not prevent the development of social skills, but social interactions do require communication to initiate and respond with specific content, which underlines the importance of matching supports to the child or young person's communication skills.[118]

Explicit teaching of social behaviour needs to be part of the individual plan for any child or young person on the autism spectrum throughout his or her life.[213, 228, 245]

Children and young people with less obvious support needs

Despite their command of language and sometimes their desire to interact, autistic children and young people with fewer and less complex support needs are often unable to use their skills to successfully enter the social fray.[245] These children tend toward repetitive enactments of solitary routines around their focused interests and either avoid social play or approach peers in ways that are unlikely to be reciprocated.[247]

Older children and young people have difficulty with peer relationships and demonstrating social and emotional reciprocity.[248, 249] Social difficulties are thought to be a reason for the high rates of depression, which are often seen in autistic adolescents with less obvious support needs.[245, 250] In adolescence, young people begin to engage in social interaction primarily by conversation and this provides many challenges for the young autistic person/tangata whaitakiwātanga.[245]

Approaches to supports

Supports to enhance social development need to be carefully planned and systematic.[251] Particular care should be given to planning for generalisation and maintenance.[118, 228, 252] 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 particular settings. It is also important to match the approach to the developmental level and needs of the particular child.[118] Researchers advocate that it is important for teachers and other professionals to try and appreciate their student's view of the world when planning supports.[247]

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.[118, 252]

Play is an important social activity for children; therefore, play skills also need to be assessed.[118] Researchers recommend an assessment of the sensory preferences of very young children.[251] 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.[213, 245, 252]

Assessment techniques and tools

Developmental scales may also be useful for assessing general social development. However, autistic children often do not demonstrate typical patterns of development.[118]

Many researchers report that the ability to carry out targeted observations is a key skill for practitioners.[243, 247, 253] 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.[247] Observations need to include the child's actual behaviours, including:

- initiations
- responses
- length of rounds
- interest in others
- proximity to others.[118]

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 supportive approach.[253]

Observations using the type of narrative assessment with which early childhood teachers in Aotearoa 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[118, 228] (*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.[118, 251] 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.[251]

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.[118, 253] Social understanding of routines and other social events needs explicit teaching and should be given equal importance to the teaching of the skills themselves.[254]

Goals need to consider family and whānau preferences and be functional in the present setting or the next environment that the child or young person will enter[118, 237] (*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.[237]

Teaching strategies

Approaches to developing social skills in young children tend to come from two broad approaches to teaching: developmental and behavioural.[118]

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'.[255] Many of these supports 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.[118] These techniques, with their emphasis on compliance, often do not acknowledge the child's initiations and often do not generalise to other settings.[247]

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.[118, 213, 237, 251]

Instructors

Supportive approaches 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 supports

Individual supports

These can be adult-directed behavioural approaches that focus on specific skills, or more child-centred developmental approaches.[118] The focus of these is usually one-on-one. If one-to-one support 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.[228]

Social skills groups

Social skills groups are a common approach. They are often used with children and young people who 'have speech' (i.e., can consistently rely on speech for functional communication) but need support to develop appropriate pragmatic language skills. These include 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.[213]

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 improve the participant's mood and self-image.[213]

Research on social skills groups for young people and adults was updated as part of the Living Guideline process. It is summarised in Appendix 3.6, and is available as full text from Whaikaha – Ministry of Disabled People's website.[20] (*Also see new Recommendation 4.2.1a, and new Good Practice Points 4.2.1b and 4.2.1c in Part 4.*)

2. Peer-mediated techniques

Peer-mediated techniques are the best developed and most studied of all the supports.[213, 228] These techniques involve trained peers, usually without disabilities, prompting and sustaining social engagement.[118, 228] These techniques have the advantage of not requiring the autistic child to generalise from an adult instructor to peers.[213] Non-autistic peers are taught to initiate such skills as 'play organisers' – sharing, helping and using praise and affection.[118]

Peer mediators need to be friendly, outgoing, and skilled, and their preparation and support are important. Instruction, feedback, and role play are important elements to use when preparing peers.[243] Supports work best when several mediators are used, so that each target child has repeated opportunities to interact with several skilled peers.[245] Support and training for the education professionals who will be involved in developing peer-mediated programmes are also required (*Good Practice Point 6.25: Professional learning and development*).

Many of these peer-mediated supports tend to be rejected by teachers because they are seen as being unduly complex and time-consuming.[245] However, simpler peer-based approaches, such as ‘Stay, Play, Talk’, show promise with younger children and are easier to set up.[245]

The effectiveness of peer-mediated strategies has been demonstrated in many studies where supports were well planned[118, 213, 228, 253] (*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.[213, 228, 243]

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 autism-specific education and support for peers.[245]

3. Combination of strategies

Some successful approaches combine both individual child-focused supports and peer-mediated supports to prompt and reinforce the strategies already taught.[228] These combined strategies have shown positive results as well as promising outcomes.[118]

Setting for approaches

Supports are most effective if they take place in natural settings and within regular routines and activities and involve opportunities for interactions with non-autistic peers.[118, 228, 245, 252, 253] The social competence of peers is a major factor associated with improved outcomes.[213] However, simply placing children and young people in settings with socially more competent peers will not be sufficient to foster social interaction without other supports.[228, 245]

The context for instruction needs to be developmentally appropriate.[245]

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.[247] Toys and activities need to be chosen with consideration for the child’s interests and preferences.[251] 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.[228]

Older students

School-aged children and young people require appropriate games and buddy systems.[245] 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.[213] However, another study reported positive outcomes from teaching symbolic pretend play. The support involved video feedback and observation and gradually reduced the amount of structure provided by the teacher.[256] Teenagers respond best to discussion groups on a variety of topics and social network supports. Both approaches should include peers who are supported by adults and, where necessary, trained.[245]

Other considerations

Supports to enhance social interactions need to be carried out in conjunction with communication supports.[118] Social interactions with both adults and peers need to be targeted.[118] There is a greater likelihood of social interactions occurring in preferred activities which have a structure and are predictable.[228]

The hidden curriculum

Autistic children and young people will need to be taught the unwritten rules of school life, such as what to do where, when and with whom. These rules tend to change depending on the circumstances and autistic children and young people will not usually be able to generalise what they have learned to different situations. Even autistic students with less obvious support needs may 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.[118, 254]

Sexuality education

Tailored sexuality education, particularly when delivered individually and intensively, should be considered for young people on the autism spectrum (*see Recommendation 3.2.2.6a*). Given the social and communication challenges associated with autism/takiwātanga, people on the spectrum can misinterpret social cues and language and have a greater openness about sexuality and sexual behaviour. This can sometimes lead to vulnerable situations or 'behaviours of concern' for people on the autism spectrum.

Sexuality education programmes aim to encourage healthy sexual development, address 'behaviours of concern', and reduce the risk of exploitation, abuse, and victimisation. There is evidence that sexuality education programmes that are tailored to people on the autism spectrum can improve psychosexual knowledge, at least in the short term.

Research on sexuality education for young people was updated as part of the Living Guideline process. It is summarised in Appendix 3.9, and is available as full text from Whaikaha – Ministry of Disabled People's website.[23] *(Also see new Good Practice Points 3.2.2.7a, 3.2.2.7b, 3.2.2.7c, and 3.2.2.7d)*. It is not currently possible to recommend the content, components and teaching strategies of sexuality educational programmes for young people on the autism spectrum. More research is needed. However, some aspects found to be helpful in relation to cognitive behaviour therapy (CBT) may also apply to sexuality education (*see Recommendation 4.3.10a*).

It should be noted that whilst much research relates to adolescents, gender identity and sexuality is expressed throughout the lifespan and targeted sexuality education may also be useful for older people on the autism spectrum.

Caveat: Sexuality education does not refer to situations where an alternative approach is required to target illegal or harmful behaviour.

Generalisation and maintenance

The teaching of skills by themselves will seldom be effective if generalisation to other settings and people is not actively addressed[250] (*Recommendation 3.2.2.5*). Supports need to be available throughout the day and in a variety of activities.[228] 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.[253]

Other approaches which have anecdotal support

Social stories

'Social stories', developed by Gray and Garand, is another educational approach[231] (*see also Appendix 8: Educational approaches*). 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.[254] 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.[245, 257] Other studies have demonstrated the utility of this approach 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.[237] There is a need for further research to consider which children and young people will benefit from such approaches.[258]

Other approaches

Other techniques that are useful for improving social skills include:

- visual cueing – printed cues in work schedules to stimulate social initiations with other autistic peers
- social games – teaching socio-dramatic scripts or games revolving around a child's focused interest (both approaches 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 (e.g., 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.[213, 245, 254]

Other issues

Approaches for home settings

Without family/whānau involvement, supports are unlikely to generalise to home and community settings.[251] Several studies have shown measurable improvements from simple supports such as teaching parents and siblings to imitate a child in play with toys and other play skills daily, or daily early childhood education service programmes with positive child-adult interactions and play.[118, 237, 243] Support and education should be provided for families and whānau to facilitate the use of home-support strategies (*Recommendation 3.2.2.6*).

Strategies can include:

- rehearsing scripts and variations
- videotaping conversations, reviewing and coaching
- structured 'play dates' (social opportunities with peers usually conducted within the home)
- structured conversations
- involvement in groups around a focussed interest.[213]

Siblings can also be involved in home supports using many of the peer-mediated techniques.[213]

3.2.c Sensorimotor 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 autistic children experience sensory and motor difficulties at some point in their development.[118, 188, 237, 243, 259] 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).[118, 188] 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[188] (*see also Part 2, section 2.3.g: Sensory processing*).

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

- hypo- or hyper-responses
- challenges in modulating arousal
- preoccupations with the sensory features of objects
- perceptual distortions
- paradoxical responses to stimuli.[188]

There is some evidence that auditory processing difficulties are a particular problem; in one study, these were demonstrated by all the subjects.[188] Visual-spatial skills appear to be more advanced than other skills, although individual differences are apparent.[188]

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.[118, 259]

Although motor skills are generally more advanced than language or social skills in autistic children, motor difficulties 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.[188]

Approaches to supports

A systematic review of the efficacy of sensory and motor supports for autistic children identified different types of programmes/strategies:[188]

- remedial approaches, i.e., ones that target specific sensorimotor components, for example, sensory integration and later developments such as sensory diets, visual therapies and Irlen lenses
- task and environmental modifications.

Some of the supports reviewed have questionable rationales for using with autistic children 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 supports 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 support or learning skills associated with the support (such as play-coaching, structured teaching and attention skills).[118, 188]

Given the variability in developmental profiles of autistic children, 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.[188] An expert professional would be someone such as an occupational therapist or physiotherapist who has autism-specific education and experience in sensory and motor difficulties (*Recommendation 3.2.3.1*).

Supports should be provided in short-term increments, progress should be systematically documented, and the support should be discontinued if some progress is not apparent within 6 to 12 weeks (*Recommendation 3.2.3.2*). As with other approaches, best practice suggests that supports are most effectively integrated into daily routines within naturalistic contexts to increase retention and generalisation of the skills.[118, 188]

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[188] (*Recommendation 3.2.3.3*).

(*Other sensory motor supports such as music therapy and sensory integration are discussed in Part 4, section 4.5. Art therapy is 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 a parent report. This should still be used in conjunction with observation data and other measures.[189, 259] 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 autistic children and young people[254]

Sensory system	Description	Some behaviours that might be observed
Vestibular	Movement of body in space	• Motion sickness • Fear of heights • Avoidance of balancing activities or participation in sports • Seeking fast-moving activities • Engaging in frequent spinning, bouncing or running • Seeming oblivious to the risks of heights or moving equipment
Tactile	Provides information about factors such as touch, pressure, texture, hard/soft, sharp, dull, heat/cold, pain	• Avoidance of touch contact • Disliking and avoiding messy play • Disliking having hair brushed or washed • Appearing irritated by certain clothing and food textures • Appearing irritated by others’ proximity • Appearing fidgety or active • Using hands to explore
Proprioceptive	Provides information about where a certain body part is and how it is moving	• Enjoying rough-and-tumble play • Relaxing when given firm touch or massage • Exerting too much or not enough pressure while handling objects

Sensory system	Description	Some behaviours that might be observed
Visual	Provides information from the eye about objects and people	• Discomfort in strong sunlight • Sensitivity to television/computer screens ortypes and changes in lighting • Enjoying or disliking flickering objects (e.g., computer, flicking pages, flickering hands) • Focusing on shadows, reflections or spinning objects, lines, patterns
Auditory	Provides information about sounds in the environment	• Becoming upset at loud or unexpected noises • Humming or singing to screen out unwanted noise • Unusual responses to voices • Dislike of large indoor spaces • Fleeing the area and refusing to go back • Sensitivity or dislike of certain sounds because of hearing sounds at a level most people don't hear (e.g., hearing the humming of lights)
Olfactory (smell) or gustatory (taste)	Provides information about different types of tastes or smells	• Dislike of strong smells or tastes • Craving strong smells or tastes • Eating non-edible items (sometimes referred to as ‘pica’) • Eating a restricted range of foods

How sensory challenges impact on daily performance is complex, and individual and sensory difficulties 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 key autistic characteristics. Occupational therapists and other staff skilled in the autism spectrum 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. An Aotearoa New Zealand survey of staff associated with early childhood education centres reported that children with auditory processing problems such as autism were the most severely affected by noise. Under noisy conditions, there was distraction from learning tasks and difficulties in communication.[260] 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.[118 188] Environmental analysis and adaptations and teaching the child or young person coping strategies (such as sensory stories)[261] are therefore the priority approaches 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 autistic children and young people can alter significant behaviour challenges by reducing negative sensory reactions. Children usually have some sensory sensitivity which can be helped by adaptations as follows:[262]

- *Acoustics:* Sensitivity to noise in autistic children and young people 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 throughout 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 short periods of time there. Other children may be helped by allowing them to wear headphones or earplugs.
- *Lighting:* for some autistic children and young people, 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 autistic students to access learning. In a mainstream school setting, the needs of a child or young person on the autism spectrum 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: • IQ tests, when used, should be accompanied by an assessment of language and an assessment of adaptive functioning in natural settings. • Cognitive assessments should be administered by a psychologist with experience and training in the autism spectrum.	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 autism 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.[263]

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 that appear at an early age.[89, 118] Later, difficulties with combining and integrating different kinds of information become more obvious. In formal cognitive testing, abilities that require less verbal mediation (e.g., block design) tend to be less affected.[118] Across time, children may learn to compensate for these difficulties, through teaching or development of their own strategies.[118] However, as in other areas of development, autistic children and young people will vary greatly in their abilities and approaches to learning and require individualised supports.[237]

About 10% of autistic children 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 non-autistic children. They are often related to the child's particular preoccupations or focused interests, and can sometimes reflect information-processing skills other than just rote-memory skills.[118]

Types of research

Research focused on understanding the cognitive characteristics of individuals who are autistic is developing rapidly and new papers are published constantly.[89] This work, however, is far from complete, and there is only a partial understanding of the basis of the behaviour of autistic people/tāngata whaitakiwātanga.

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.[89] 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 autism. However, clearly some systems are unaffected, as is demonstrated by typical or superior functioning in some areas by some individuals.[89]
- **psychology** has provided some theories to explain the cognitive characteristics and behaviours of autistic children and seeks to explore and refine these hypotheses with experimental data.[89]

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 autistic children and young people. However, the growing body of evidence does provide some directions for educational practice.

Implications for professional practice

How cognitive abilities and challenges are interwoven with social and communication difficulties for each child means that no educational support 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 autistic children has been assessed traditionally using IQ tests. The information about IQ in populations of individuals diagnosed with ASD has changed. Up to 70% were considered to be intellectually disabled, whereas current estimates suggest that fewer than half of autistic children have 'non-verbal IQs' less than 70.[89, 118] 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.[118] IQ scores are relatively stable with older children, but problematic with very young children and those who have higher and more complex support needs.[118]

There is debate about the role of IQ testing for this population.[264] There are difficulties in assessing autistic children 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 that may be inappropriate.[14]

There are also challenges in interpreting the results. The scatter of abilities that often appears in the profile of autistic children means that composite scores are misleading.[118]

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.[14]

Suggestions for assessment tools

IQ tests, if used, should be one of several measures and a language assessment should always be included to establish whether some difficulties might be due to difficulties in following instructions[264] (*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.[118] 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 over- or under-estimate abilities but these can be confirmed with direct observation. Observations should be made in both structured and unstructured settings.[14]

Tests and other cognitive assessments should be administered by a psychologist with experience and training in the autism spectrum (*Recommendation 3.2.4.1*). The setting needs to be chosen with particular care[14] and extreme care is required when interpreting test scores, particularly with younger children.[244, 264]

IQ tests should not be considered the primary measure of outcome for supports because there are very complex implications for test selection in this population across ages and developmental levels.[118] When IQ scores are used as outcome measures for supports, 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.[61, 265] Also, some apparent changes may reflect an increase in compliance rather than a true change in cognitive ability.[14]

Evaluation of academic skills is very important for planning goals for children who are participating in academic activities.[118]

Teaching strategies

Autistic children 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 based on 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[118] (*Recommendation 3.2.4.2*).

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

Autistic children 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 autistic children to learn in areas where they have no interest and, as a consequence, no prior knowledge.

In this context, Steven Shore (Autistic academic and advocate) notes that:

> *Teachers need to know about their student's 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*[266] (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[237] (*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[244, 267] (*Recommendation 3.2.4.4*).

4. Provide structure in the classroom programme

Autistic children and young people often require much more structure in their environments than others to learn.[14, 237, 266] '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 that 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, routines, and warnings (including visual ones) about transitions and changes.[237, 241, 244]

5. Supports for older children and young people

Preparing the student for what is going to happen offers several 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[237, 241] (*Recommendation 3.2.4.5*).

3.2.e Self-management skills and addressing 'behaviours of concern' in education settings

Summary of recommendations

Recommendations and Good Practice Points:		Grade
3.2.5.1	Supportive approaches should start early, before or as soon as 'behaviours of concern' are observed, and be proactive. The child or young person's programme should be culturally responsive, individualised, and designed to engage the child or young person and provide a highly supportive environment.	B
3.2.5.2	Educational supports should incorporate principles of positive behaviour support, particularly a focus on understanding the function of the child's behaviour (*see Appendix 3.1*).	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 or support plan.	C
3.2.5.5	Teams in educational settings benefit from responsive service support when teaching students with very complex, potentially harmful behaviours. This may include both behavioural specialists and health sector supports.	✓

Background

‘Behaviours of concern’

‘Behaviours of concern’ are behaviours of people that may be a problem for the autistic individual and/or for others. These behaviours can include hurting themselves, hurting others, breaking things, refusing to do things, doing the same thing over and over, doing things others don’t like (e.g., screaming, taking off clothes), or hiding away. This behaviour can stop the autistic child from doing things that other people do, like going to school or seeing their friends. These behaviours can be very stressful and upsetting for everyone involved, either directly or indirectly.

‘Behaviours of concern’ have been identified as the most challenging and stressful issue facing parents and educators of autistic children and young people.[118, 213] There is evidence that for autistic children, unlike for non-autistic children, once established, such behaviours may persist and worsen rather than decrease with age.[118, 268]

Behaviours of concern are sometimes called ‘challenging behaviours’ or ‘problem behaviours’. However, it is important to understand that what is a ‘problem’ or ‘the challenge’ depends on whether one looks at the behaviour from the perspective of the autistic individual or the perspective of the person witnessing the behaviour.

From a child’s perspective, parents and teachers demonstrate ‘problem behaviour’ by putting the child in situations that they find difficult, by:

- making excessive demands (from the child's perspective)
- 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
- putting the child in a challenging sensory environment (e.g., noisy classroom, shopping mall, etc).

From the parent’s or teacher’s perspective, the child demonstrates ‘problem behaviour’ by not complying, disrupting classroom activities, having what is regarded as 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, educational, and community activities and therefore need to be understood and addressed.[118]

It is important to remember that it is the behaviour that is the problem, not the person. And in some situations, the behaviour itself may not need to be changed, but rather the environment (e.g., removing sensory irritants), or the non-autistic person’s understanding of the child’s behaviour. This is particularly relevant when considering stimming which can be pleasant, sensory-seeking, and/or not problematic for the autistic individual. Efforts to force eye contact or ‘quiet hands’ are misguided and may be damaging to the autistic child.[269, 270]

As the words ‘problem’ and ‘challenging’ can appear judgemental and pejorative with respect to the autistic individual, in the Guideline the term ‘behaviours of concern’ is used *(see the section ‘Autistic perspectives’ in the Overview, for further information).*

The focus of supports

The nature of behavioural supports has changed over the 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 changes to systems within the organisation. There should no longer be an emphasis on deterrence or punishment.[213]

An extensive meta-analysis found that supports that focused on teaching positive skills to replace 'behaviours of concern' combined with system change had better outcomes than consequence-focused supports.[271] 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 autistic children and young people. Principals and staff will need to resolve this issue so that all adults support the child's behaviour or support 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 'behaviour of concern'.[118]

There is agreement that approaches are most effective if they begin early, before 'behaviours of concern' become entrenched. The child should not be left to 'grow out of the behaviour.'[14, 213, 268] The child or young person's programme should be culturally responsive, individualised, and designed to engage them and provide a highly supportive environment (*Recommendation 3.2.5.1*).

The use of punishment and physical restraint

Punishment is the use of an aversive procedure in an attempt to eliminate or reduce unwanted behaviour. Approaches 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[118, 213] (*Recommendation 3.2.5.3*). Unjustified physical restraint is not permitted in a school setting. There are thresholds to be met before physical restraint is permitted.

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 autistic children enjoy being alone and are not worried about social exclusion. As a result, this approach 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 support plan should be developed within this policy for each child at risk. This should outline details of procedures, including when they will be used, and be agreed to by the parents/guardians.

The Education (Early Childhood Services) Regulations 2008 make it clear that physical restraint is not permitted.

For schools and kura, an update is planned to the Education and Training Act 2020[272] with respect to rules and guidelines relating to restraints as "physical force to prevent, restrict, or subdue the movement of the student's body or part of the student's body against the student's will". The latest updates can be viewed on the website dedicated to this mahi.[273]

Positive behaviour supports

To promote positive behaviour supports or approaches it is necessary to first consider the supports that may be required by the autistic student; or changes that may be required to the environment to enhance their opportunities for learning. Positive behavioural supports or approaches also need to ask what the child can do instead of the 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 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 replaces one 'behaviour of concern' with another to serve the same purpose.[213]

Positive behaviour supports impact on many areas of practice.

(a) Preventing or minimising 'behaviours of concern'

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.[118, 229, 244, 268]

Autistic children who have educational programmes that effectively target appropriate pro-social and positive skills (communication, social interaction, cognitive, adaptive behaviour and sensorimotor skills) are less likely to develop 'behaviours of concern'.[14, 118] Given that these skills are difficult for this population, many children are at risk of developing alternative ways of coping (often with 'behaviours of concern') as a response to difficult situations if they do not receive proactive supports and teaching.[268] Increasing engagement in activities, providing limited choices, and using preferred materials and topics are also effective prevention strategies for young children.[229]

Augmentative communication strategies to help with receptive and expressive communication (e.g., 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[14, 118, 229] It is equally important that these supports are kept up to date and are not removed without careful consideration.

Physical activity[25] and relaxation strategies have been shown to have health benefits and can help prevent 'behaviours of concern', particularly those related to self-stimulatory behaviour[118, 188] (stimming) and disruptive behaviour.[265] *(Note that research on physical activity was updated as part of the Living Guideline process, and is summarised in Appendix 3.11, and available as full text from Whaikaha – Ministry of Disabled People's website.)*[25]

Again, it is important to consider whether the stimming behaviour is a problem for the autistic person (i.e., getting in the way of desired activities, learning, social interactions, etc) or is one that people around them simply don't want because they feel uncomfortable. In such situations, the autistic person shouldn't be doing the changing.[269, 270] If the behaviour is dangerous for the child or others around them, or inappropriate, then an active strategy or plan may be required.

Preparing for and supporting children and young people through transitions, both between activities and different settings, are important to minimise stress and anxiety.[237]

The provision of a quiet space is important for most autistic children and young people. 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 'downtime' as a reward that is dependent on performance can increase anxiety and behaviours of concern and should be avoided.

In summary, the key to avoiding and reducing 'behaviours of concern' (where they are truly unwelcome) is to provide an appropriate individualised education programme to engage the child or young person[118, 229, 268] (*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 'behaviours of concern'

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.[118, 268, 274] 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, i.e., the antecedents and consequences which may be supporting the behaviour.[213, 229, 237, 275] An appropriate behaviour or support plan can then be developed.

It is important to acknowledge the role the key areas of an autism diagnosis (social communication and social interaction, and a lack of flexibility in behaviour, interests, or activities) may play in causing or maintaining the 'behaviour of concern'. Many such behaviours may have communicative and social functions for the child or be an attempt to control their environment (for example, to address sensory sensitivities). Once the function of the behaviour has been established, the child may be taught a more appropriate behaviour that 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, wants or distress
- 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.[118]

The steps in a functional assessment are:

- describe the 'behaviour of concern' 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 a supportive approach ot strategy ('intervention'), supported by the assessment, to provide an alternative behaviour.[118, 268, 274]

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.[274] 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-occurring conditions such as epilepsy.[14] 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.[118] 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.[61]

This assessment and analysis may lead teams to develop hypotheses about causal relationships between environmental changes, skill acquisition and reductions in the targeted 'behaviour of concern'. 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 the behaviour as well as the skills needed by the child.[274, 276] 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.[118, 268] However, the research warns that in some cases where assessments were conducted, supports were designed that were not consistent with the actual assessment information. This highlights the need for education to effectively link assessment and support.[268, 277]

Research has shown that positive behavioural approaches and supports:

- are effective in significantly reducing 'behaviours of concern'
- 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[268] (*Recommendations 3.2.5.2, and 6.9: Professional learning and development*).

One study that trained parents to analyse 'behaviours of concern' in their young children and teach their children functional communication systems (based on their existing communication skills) increased appropriate social behaviour by 69% and decreased aberrant behaviour by 87%. The support took 10 minutes a day and had a high rating for parent acceptability.[118]

(c) Teaching positive skills

Comprehensive behaviour or support plans are supportive strategies that have been developed by the team around the child.

Comprehensive behaviour plans should:

- consider all 'behaviours of concern' performed by a child
- be driven by functional assessment outcomes
- be applied across all (or most) of the child's day
- incorporate several supportive 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.[268]

(a) Generalisation

It is no longer considered appropriate to reduce 'behaviours of concern' in narrow contexts across narrow periods. Good supports result in adding elements to the child's life that improves the richness or effectiveness of living and learning. It is therefore very important that all those who will interact with the child (e.g., other teachers, relieving or duty teachers) have an understanding of the young person's behaviour or support plan and goals[276] (*Recommendation 3.2.5.4*).

(b) Organisational systems

Effective supports require funding for staff development (*Recommendation 6.10: Professional learning and development*). Staff time and evaluation should be available to support these practices.[118, 268, 275] There can often be a conflict between school behaviour management policies that have a focus on punishment or negative consequences (e.g., detentions) and positive behavioural supports. 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 behaviour and adapt to the learning, physical and social environment to produce a durable change in the behaviour of the children. Teachers, families and whānau, and staff may need to be trained to consider elements such as:

- adapting the curriculum
- modifying daily routines, the timing of activities and the spaces or places used
- ensuring adequate opportunities for social engagement
- changing communication styles
- following through with planned supports
- monitoring the effect of supports[118, 213, 268, 275] (*Recommendation 6.11: Professional learning and development*).

Environmental change

Behavioural supports should 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.[118, 268]

Other issues

Outcome measures

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

- a reduction in the 'behaviours of concern'
- child or young person's use of new alternative skills that they can now use in place of the 'behaviours of concern'
- evidence of new strategies to prevent future difficulties in similar 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).[278]

More serious behaviours

A small number of autistic children and young people may develop very serious or dangerous behaviours.[116] When this occurs, rapid access to specialist assistance and support and a timely response is essential. This may include both specialist health and behavioural assistance (*Good Practice Point 3.2.5.5, and see Part 4, section 4.6: Supporting people with 'behaviours of concern'*).

3.3 Particular issues for secondary students

Summary of recommendations

Recommendations and Good Practice Points:		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
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 autistic children focuses on the needs of younger children. Strategies for supporting young people at secondary school are often derived from research on younger children. Further research work needs to be done on the particular issues associated with secondary schools and particularly in meeting the needs of young people with higher/more complex support needs.

There are particular challenges in providing a suitable programme and meeting the support needs of autistic young people 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 perceptions and needs
- students' difficulties in understanding the needs of others and ways of meeting them
- lack of motivation
- increased expectations around independence
- difficulties because of the emphasis on assessments. When young people suffer from stress or have difficulties understanding questions or instructions, they may not demonstrate abilities consistent with the assessment[279] (*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.[279]

Transitions

Good transition experiences prior to starting secondary schools can be helpful and require planning by schools, parents, and the autistic young people

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 in 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[241] (*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 secondary school (*Good Practice Point 3.3.3*). For further discussion about transitions, *see section 3.4: Education sector organisation and management and specifically Recommendation 3.4.5*.

There may need to be consideration and planning for special exam and assessment conditions and the transitions required for this.

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 workplace. Functional academic skills and problem-solving must be also included. At this stage, however, there must be an emphasis on the young person's particular interests and strengths in developing his/her curriculum[244] (*for further discussion see Part 5, section 5.1: After secondary school*).

3.4 Education sector organisation and management

Summary of recommendations

Recommendations and Good Practice Points:		Grade
3.4.1	All school staff should be offered information about autism 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 autism 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: • structure • opportunities for contact with non-autistic peers • trained and stable staff • staff with a positive attitude • willingness of all staff and management to work with family/whānau as a team • flexibility to meet changing needs • a culturally responsive environment (*see Appendix 3.8*).	C
3.4.4	Education for autistic students in Aotearoa New Zealand schools should have the following elements: • individualised supports and services • systematic instruction • comprehensible and structured learning environments • specialised or adapted curriculum content • a functional approach to ‘behaviours of concern’ • family/whānau involvement • culturally responsive approaches (*see Appendix 3.8*).	B

Recommendations and Good Practice Points:		Grade
3.4.5	All transitions for students on the autism spectrum should be carefully planned and include the following: • Identifying a key education professional early in the transition process to guide children and young people and their family/whānau, and provide an ongoing point of contact • Person-centred planning involving children and young people in decisions about the transition, respecting their views, and individualising their plans • Having team transition planning meeting/s, preferably beginning 6–12 months before transition, involving family/whānau, key staff from both sending and receiving schools, and other supporting team members • Developing a student profile in collaboration with the child/young person and their family/whānau to inform current and future school teams. The profile should include the child/young person's strengths, interests, needs, behaviours, preferences, and successful strategies • Having transition visits for the child/young person to their new school environment to provide familiarisation, establish relationships, and alleviate anxiety • Using visual supports appropriate to individual needs, for example: – a map of the new school – photographs, pictures, and social stories, possibly incorporated into an induction booklet – visual schedules, including calendars, timetables, diaries, and planners that present the routines of each day – Providing social supports and environmental adaptations such as a safe person, peer buddy, adult mentors, and a safe space – Having regular, constructive, culturally appropriate, and respectful communication between teachers and family/whānau – Sharing support strategies across school and home environments (*see Appendix 3.10*).	B
3.4.5a	Many strategies recommended in Recommendation 3.4.5 are applicable to within-school transitions (e.g., between year levels and other transitions) (*see Appendix 3.10*).	✓

The support of the whole school community is a key factor in the successful education of a child or young person on the autism spectrum.

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

Support from management

Teachers and specialist educators who work with autistic children and young people 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.[224] Teachers require support from school management for professional learning and development and release for consultation with specialist autism support staff.[224] School-wide policies need to be reviewed with consideration of the implications for students with learning support needs.[118]

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

Whole school awareness

The child or young person on the autism spectrum benefits both from a consistency of support 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.[14, 118] All members of staff require information, experiences and opportunities for discussion to help them foster more accepting attitudes towards autistic individuals[224] (*Recommendation 3.4.1*).

Support for peers

If interactions and relationships with peers are to be successful, the other students require support and information[118, 212, 279] (*Recommendation 3.4.2*). Units of work and simulations designed to facilitate a better understanding have proved effective.[267] 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 autistic child when he or she is anxious or upset and to be aware of his or her particular interests.[279] Decisions about what others are told about the individual child need to be made with consideration of the views of the family/whānau.[118, 212] Staff should be particularly alert for signs of bullying of autistic students.

Many autistic students do not receive additional support from the Ministry of Education through current learning support initiatives. Given the complex nature of this condition, it is likely that all students will require access to some autism-specific specialist service at some point.

Support for teachers

The research repeatedly emphasises that there is no one programme, strategy or level of intensity to meet all the needs of all children and that individualised programmes of support are the most appropriate.[118, 237]

To understand the needs of students, provide autism-specific assessments, supports 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 their autistic children. 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 into account the needs of the child as well as the preferences of the family/whānau and what options are locally available.[14, 267] Options for autistic students 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 some services for students with learning support needs and some families opt for homeschooling. The correspondence school current funding model doesn't always leave them in a position to provide all learning support services for students with learning support needs. Not all these choices will be available to families.

Schooling in Aotearoa New Zealand: A guide states:

Learning support 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 learning support needs can receive help in a range of settings, including special schools, learning support classes in regular schools and mainstream classrooms. Most students with learning support needs attend a regular school.

Parents and caregivers of children with learning support 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.[280]

The evidence for autistic children 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.[14, 118] Each child should be accommodated in the least restrictive setting required to still meet that student's needs (i.e., as close to a regular school setting as possible). A more restrictive environment may be required for students with severe behavioural challenges 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 of autism 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 autism, children can be adversely affected and may not make good progress academically or socially.[14]

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.[279] The development of peer-mediated supports is particularly helpful.[118, 224]

For regular education placements to be successful, educators require knowledge of and access to empirically validated strategies and professional supports.[267] Settings need to provide sufficient structure to support the child or young person.[14, 118]

Placement decisions must 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 non-autistic 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 can be flexible in meeting the child's needs over time
- where the autistic child can cope with the environment from a sensory perspective
- and is provided in a culturally responsive environment (see *Recommendation 3.4.3, and Appendix 3.8*).

3.4.b Implications for the Aotearoa New Zealand school sector

The literature for early childhood includes variable age ranges, with some studies covering up to the age of seven years.[14, 118] 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 careful 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.
- Comprehensible and structured learning environments

  This includes strategies such as organising the instructional setting, providing a schedule of activities that are 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 key difficulties for autistic individuals in the areas of communication and social interaction, and the skills that are required to participate.
- Functional approach to 'behaviours of concern'

  This describes the process by which the child/young person's 'behaviour of concern' is not merely decreased or eliminated, but is replaced with an appropriate alternative or replacement behaviour that results in the same or similar consequences, with appropriate support (*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[237]

- Culturally responsive approaches (*see Recommendation 3.4.4*, and note that research on ethnic culture was updated as part of the Living Guideline process, is summarised in Appendix 3.8, and available as full text from Whaikaha – Ministry of Disabled People's website).[22]

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

Collaborative teams in education

Developing and maintaining effective collaborative learning support.[118] Most teams will consist of core members who will generally include the student's classroom teacher, special education needs coordinator (SENCO), Learning Support Coordinator, 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:

- a genuine partnership between schools and parents
- 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.[281]

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.[281]

The roles of specific professionals

The education section of the 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 autistic children and young people in a variety of settings.

Members of a well-functioning collaborative team will share information and skills. 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 autistic students. 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[231]
- careful analysis of difficulties (not always what is assumed).[224, 232]

Developing, regularly updating, and using 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.

For further discussion of transitions see sections 3.1 and 3.3 and Recommendation 3.4.5. Research on school transitions was updated as part of the Living Guideline process. It is summarised in Appendix 3.10, and is available as full text from Whaikaha – Ministry of Disabled People's website.[24] This update relates to transitions to and between primary, intermediate and secondary schools and school levels. Part 5, Section 5.1 related to post-secondary school transitions.

Part 4

Supportive approaches for mental health and wellbeing

“Mā te huruhuru ka rere te manu”

Feathers allow the bird to fly

Part 4: Supportive approaches for mental health and wellbeing

This section covers supports for mental health difficulties that can be experienced by children, young people, and adults on the autism spectrum, and promotes wellbeing. Many of these difficulties can be prevented, minimised, or alleviated by supports with an educational component (*see Part 3: Education for learners*). This section applies to supports with a different focus.

4.1 Introduction

Summary of recommendations

Recommendations and Good Practice Points:		Grade
4.1.1	Supportive approaches should encourage functional development, teach skills for independent living, and minimise stress for the autistic person, and their family and whānau.	B
4.1.2	Supportive approaches for autism and co-occurring conditions should be matched to the specific characteristics and needs of the person concerned.	B
4.1.3	Supportive approaches for autism and co-occurring conditions should be based on comprehensive diagnostic and ongoing assessments.	B
4.1.4	Prior to commencing a new supportive approach, assessments should gather detailed information on behavioural, emotional and mental health difficulties, address differential diagnosis, screen for medical conditions, and address cultural and environmental issues (*see Appendix 3.8*).	B
4.1.4a	Gastrointestinal problems, specifically constipation, chronic diarrhoea, altered bowel habits, and encopresis (faecal soiling), are more common in autistic children and young people compared with non-autistic peers (*see Appendix 3.4*).	B
4.1.4b	Autistic children and young people 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 (*see Appendix 3.4*).	C
4.1.5	Support plans should be comprehensive, and include behavioural needs, educational programmes, psychosocial approaches, communication, environmental, cultural and systems issues, and the suitability (or not) of medication (*see Appendix 3.8*).	B
4.1.5a	Supports should be accessible and appropriate to people from ethnic minority communities. This will require proactive measures (*see Appendix 3.8*).	B
4.1.5b	Professionals should collaborate with individuals on the autism spectrum and their families/whānau to set goals that are culturally responsive (*see Appendix 3.8*).	✓
4.1.5c	Professionals, when working with people of other ethnicities, should reflect on their own cultural beliefs and experiences and how these influence their practice (*see Appendix 3.8*).	✓
4.1.5d	Further research that targets meaningful outcomes for the autistic community is essential (*see Appendix 3.11*).	✓

Autism Spectrum Disorder is behaviourally defined. Working through the characteristics of autism, it is clear that behavioural and social communication difficulties typify the condition, and that long-term problems may arise if the communicative, social, and ritualistic/intensively focussed aspects of autism ('restricted, repetitive behaviours') are not attended to.[268, 282, 283] Common behavioural issues include hyperactivity, attention difficulties, repetitive and ritualistic behaviours, self-injury, tics, and unusually strong interests.[84, 284] Problems with mood are common,[84] as are social difficulties.[285] Not surprisingly, parents of autistic children and young people frequently seek behavioural advice, as do families and carers of those autistic adults who also have an intellectual disability. Good supportive approaches for autism encourage typical development and skills for independent living, while minimising the stress of the autistic person/tangata whaitakiwātanga and their family/whānau, and strategies are likely to be more successful if they are targeted on specific skills development (*Recommendation 4.1.1*).

Research outcomes to date have primarily focused on addressing the characteristics of autism/takiwātanga which are key areas for an autism diagnosis. However, there is increasing demand from the autistic community for research into outcomes that are important to them. Further research that targets meaningful outcomes for the autistic community is essential. In particular, care should be taken to avoid outcome measures that seek to eliminate autistic traits that are stigmatised but not harmful[218] (*see Good Practice Point 4.3.13*).

There is growing literature on the mental health concerns of autistic people/tāngata whaitakiwātanga. Emotional issues, such as poor anger and anxiety control and depression, appear to be common experiences of young people and adults on the autism spectrum,[285, 286] especially at times of transition and in adolescence. Major psychiatric disorders (e.g., bipolar affective disorder, psychoses, schizophrenia and catatonia) have also been described in research and academic case studies.[56, 79, 286-291] 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) were diagnosed with ASD, most previously undiagnosed.[74] The increased prevalence of psychiatric issues in the population of people with intellectual disabilities has been well established in the literature.[176] Preliminary research on the prevalence of psychiatric symptomatology in people with intellectual disabilities who are autistic and not autistic suggests that autistic individuals have a much higher chance of developing psychiatric problems.[284]

There is debate about whether the behavioural and mental health issues of autistic people/tāngata whaitakiwātanga should be considered co-occurring conditions (i.e., completely separate disorders that occur at the same time as autism) or underlying characteristics of autism/takiwātanga itself.[286, 290] Nevertheless, international guidelines for autistic children suggest that supports for autistic people/tāngata whaitakiwātanga should be distinguished from those employed for co-occurring conditions and programmes should be individualised (*Recommendation 4.1.2*). When managing co-occurring mental health difficulties, individual autistics may benefit from psychopharmacology.[287]

The first step in supportive approaches for addressing the mental health and wellbeing needs of autistic people/tāngata whaitakiwātanga is comprehensive assessment[84] 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*). Before commencing a new programme or approach, assessments should gather information on behavioural, emotional and mental health difficulties in much more detail, address differential diagnosis, screen for medical conditions, and address cultural and environmental issues before developing psychological programmes[268, 283] (*Recommendation 4.1.4*). Note that research on gastrointestinal issues in autistic children and young people (*Recommendations 4.1.4a and 4.1.4b*) was updated as part of the Living Guideline process[18], and is summarised in Appendix 3.4, and available as full text from Whaikaha – Ministry of Disabled People's website.

Supportive approaches for autism and co-occurring conditions are most appropriate when derived from comprehensive diagnostic and ongoing assessments, given that no one option works for all autistic people/tāngata whaitakiwātanga.[84, 268, 283] Components of comprehensive support plans include those that address behavioural needs, educational supports, psychosocial approaches, communication, environmental, cultural and systems issues, and the suitability (or not) of medication[84] (*Recommendation 4.1.5*). In many cases, education on autism and post-diagnosis counselling may help ameliorate various issues. However, often the behavioural, emotional, and mental health needs of autistic people/tāngata whaitakiwātanga will need to be specifically addressed.

Supports should be accessible and appropriate to people from ethnic minority communities. This will require proactive measures. Proactive measures are evidenced by individuals and organisations:

- seeking advice and feedback from members of minority cultures regarding their experiences and needs
- identifying where modifications of standard approaches are required to respond to these needs
- validating these modifications in collaboration with members of the minority culture
- undertaking to ensure that culturally responsive practices and measures become integrated and standardised within their own practice, and that of the organisation they represent
- ensuring that barriers to full participation, including training and employment, of members of minority cultures within the organisation are eliminated, and replaced with strategies that enhance participation (*see Recommendation 4.1.5a, and Good Practice Points 4.1.5b and 4.1.5c*). Note that research on ethnic culture was updated as part of the Living Guideline process and is summarised in Appendix 3.8, and available as full text from Whaikaha – Ministry of Disabled People's website).[22]

Gender and sexual diversity may also be representative of a minority community. The measures above are also relevant and recommended. See *Good Practice Point 3.2.2.7a*.

4.2 Problem minimisation and avoidance

Summary of recommendations

Recommendations and Good Practice Points:		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 children and young people on the autism spectrum with less obvious support needs (*see Appendix 3.6*).	B
4.2.2	Parents, families and whānau should be provided with information on supports that are available locally, nationally and internationally.	C
4.2.1b	Social skills groups approaches in Aotearoa New Zealand need to be responsive to the cultural and linguistic diversity of the group participants (*see Appendix 3.6*).	✓
4.2.1c	Decisions about participating in social skills groups should be guided by whether an autistic person values it, and whether they are expected to benefit from it (*see Appendix 3.6*).	✓
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 key areas for an autism diagnosis as experienced by young people and adults should be considered to minimise and avoid difficulties.	✓

Because of their social and communication challenges, autistic people/tāngata whaitakiwātanga are at increased likelihood of developing behavioural and emotional difficulties from childhood. Once 'behaviours of concern' have become established, they are not likely to decrease without supportive approaches, and are more likely to worsen than improve. Not intervening and hoping the child will outgrow such behaviours is a mistake.[268, 286] Many of the mental health, behavioural and even legal problems experienced by young people and adults on the autism spectrum arise from communication difficulties, social misunderstanding, intense focused interests, compulsions, and ritualistic or repetitive behaviours,[283] which are frequently evident in childhood. Therefore minimising and avoiding 'behaviours of concern' early in life is essential (*see Part 3, section 3.2e: Self-management skills and addressing 'behaviours of concern' in education settings*).

Given individual and family differences, no one method or style of support is likely to be effective for all autistic children and supportive approaches will need to be adapted to individual needs.[283] Accordingly, parents, families and whānau of young children on the spectrum should be supported to:

- learn about autism/takiwātanga as it affects their child, and adapt the home environment and routines accordingly
- develop routines within the home that works for both the child and the family and whānau
- 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 (e.g., 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 'behaviours of concern'.[268, 286, 292-294] Delays in accessing these specialist services can have future implications.

Problem minimisation and avoidance are equally as important for services and paid staff. Agencies providing services for autistic people/tāngata whaitakiwātanga of any age (including adulthood) can implement strategies designed both to avoid the development of 'behaviours of concern', and to intervene early, such as ensuring that members of staff have a good education in autism, that education is current, and that agency procedures incorporate best practice in autism (*Recommendation 6.17: Professional learning and development*).

Adequate service provision for young people and adults on the autism spectrum and routine monitoring may reduce the number and severity of stressors experienced by autistic people/tāngata whaitakiwātanga and, in doing so, minimise and avoid difficulties for them and others (*Good Practice Point 4.2.3*). Attention to educational, work and vocational options (*see Part 5, 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 an autistic person, which are key areas of an autism diagnosis, is frequently effective in preventing and/or managing behavioural and mental health challenges (*Good Practice Point 4.2.4*). Promising outcomes have been described for autistic adults following participation in relatively inexpensive and time-efficient social skills groups[295] and community support schemes[296-298] (*Recommendation 4.2.1*). Research on social skills groups for young people and adults) was updated as part of the Living Guideline process, and is summarised in Appendix 3.6, and available as full text from Whaikaha – Ministry of Disabled People's website[20] (*Recommendation 4.2.1a*, *Good Practice Points 4.2.1b and 4.2.1c*).

For all autistic people/tāngata whaitakiwātanga and their parents, family and whānau, information on approaches, programmes 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 autism 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 supportive approaches (*see sections 4.3, 4.4 and 4.5*).

4.3 Psychological approaches to supporting autistic people

Summary of recommendations

Recommendations and Good Practice Points:		Grade
4.3.1	Professionals should, objectively and honestly, interpret research evidence for parents or autistic people.	C
4.3.2	Structured educational/daily living programmes and supports with an emphasis on visually based cues should be implemented. They should focus on skill enhancement and establishment of communication strategies. Family-centred supportive approaches should be provided.	C
4.3.3	Professionals, autistic people, family, whānau and carers should evaluate supportive approaches before and during implementation.	C
4.3.4	Behaviour management techniques should be used to address 'behaviours of concern' following functional behaviour assessment (*see Appendix 3.1*).	A
4.3.5	All behavioural approaches should be of good quality and incorporate the following principles: person-centred planning, functional assessment, positive strategies, be multifaceted, focus on environment, meaningful outcomes, focus on ecological validity and be systems-level.	C
4.3.5a	Supports and strategies based on the principles of applied behaviour analysis should be considered for autistic children (*see Appendix 3.1*).	A
4.3.5b	Early intensive behavioural intervention (EIBI) should be considered as an approach of value for young autistic children to improve outcomes such as cognitive ability, language skills, and adaptive behaviour (*see Appendix 3.1*).	B
4.3.6	Consumers of applied behaviour analysis supports should refer to the most recent published guidelines for identifying, selecting and evaluating behaviour analyst services for autistic people (*see Appendix 3.1*, and *Good Practice Point 4.3.13*).	C
4.3.7	The feasibility of establishing publicly funded, autism-specific behavioural services should be investigated.	C
4.3.8	Insight-oriented therapy and psychodynamic therapy are not recommended as suitable approaches for autistic people.	C
4.3.9	Cognitive behaviour therapy and related approaches should be considered suitable supports for many behavioural, emotion regulation and mental health challenges.	C
4.3.9a	Broadly defined cognitive behaviour therapy, adapted for autism, may assist adults with mental health conditions (*see Appendix 3.7*).	C

Recommendations and Good Practice Points:		Grade
4.3.9b	Cognitive behaviour therapy (CBT) has been designed and evaluated predominantly for non-autistic people. 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 therapy effectiveness (*see Appendix 3.7*).	✓
4.3.10	Cognitive behaviour therapists should adapt their techniques to take into account the characteristics of autistic people.	C
4.3.10a	The following adaptations to cognitive behaviour therapy are recommended: • **Use a structured approach** and minimise anxiety about the therapeutic process by being **explicit** about roles, times, goals and techniques. • Extend the **number of sessions** and **time provided** to conduct tasks to accommodate slower information-processing and the mental demands of the therapeutic process. Be **flexible** about the length of each session and offer breaks to allow for cognitive and motivational challenges. • Provide **psycho-education** about autism/takiwātanga, emotions, and mental health challenges relevant to the client. • Concentrate on **well-defined** and **specific difficulties** as the starting point for support, with less emphasis on changing client's cognitions. • Be more **active** and **directive** 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. • Teach **explicit rules** and their appropriate context, including the use of verbal, non-verbal and paralinguistic cues to a social situation. • Incorporate specific **behavioural techniques** where appropriate, such as relaxation strategies, meditation, mindfulness, thought stopping or systematic desensitisation. • **Communicate visually** (e.g., using worksheets, images, diagrams, 'tool boxes', comic strip conversations, video-taped vignettes, peer-modelling, and working together on a computer). • **Avoid ambiguity** through minimising the use of colloquialisms, abstract concepts and metaphor. Use specific and concrete analogies relatable to the client's concerns.	✓

Recommendations and Good Practice Points:		Grade
	• Incorporate **participants' interests** in terms of content and modes of content delivery to enhance engagement. • Involve a **support person**, such as a family member, partner, carer or key worker (if the autistic person agrees) as a co-therapist to improve generalisation of skills learned within sessions (*see Appendix 3.7*).	✓
4.3.11	Approaches and strategies based on the principles of applied behaviour analysis should be relevant to the child's context and culture (*see Appendix 3.1*).	✓
4.3.12	Approaches and strategies based on the principles of applied behaviour analysis may be introduced before the diagnosis of ASD is confirmed in a child displaying some of the core characteristics of autism/takiwātanga (*see Appendix 3.1*) *(see Good Practice Point 4.3.13)*.	✓
4.3.13	In choosing a supportive approach, strategy, practitioner or therapist, the following principles for ethical practice are recommended: • **Accept the person as authentically autistic**. Respect neurodivergence as difference that does not need to be cured. • **Be strengths-based**. Identify and work with an autistic person's strengths, abilities, and potential. • **Be person-centred**. Focus on the needs and autonomy of the autistic person. Consider their culture, needs and choices in identifying an approach and its goals. • **Avoid encouraging masking** of a person's autism/takiwātanga. Do not target reducing behaviours (such as 'stims') which are not harmful or a barrier to desired goals (e.g., do not demand eye contact). • **Understand that behaviour is communication** and where harmful or 'challenging', focus on understanding its purpose and achieving positive change through alternative ways. • **Identify, encourage, and facilitate access** to use of supports, modifications, reasonable accommodations, and adjustments (rather than getting the autistic person to do all the changing) • **Presume competence and potential.** Assume an autistic person has the capacity to think, learn, and understand regardless of how they communicate. • **Provide access** to communication modalities that facilitate an autistic person's ability to process and express (e.g., augmentative and alternative communication (AAC) devices, signing, quiet space). • **Do not use** seclusion and restraint, or aversive practices (*see also Recommendation 3.2.5.3*).	✓

Recommendations and Good Practice Points:	Grade
• **Be collaborative**. Work alongside supportive family, carers, and professional providers, therapists, and educators. • **Regularly assess consent**. Look for signs of disinterest, disengagement, or distress and consider reducing intensity, taking a break, or ceasing an approach altogether. • **Monitor progress** regularly (*see also Recommendation 4.3.3*). • **Commit to the dignity, civil liberties and human rights** of people served. Comply with United Nations Convention on the Rights of Persons with Disabilities (2008) and United Nations Convention on the Rights of Children (1989).	

It can be difficult for families and professionals to work out what strategies are helpful and effective when supporting autistic individuals. Biased, misleading and even irresponsible claims are to be found all over the internet.[299] Moreover, it is important not just to evaluate the supports and strategies but also to ensure goals for the individual are appropriate and helpful for the individual in both the short and long term.

Professionals have a responsibility to interpret research as objectively and honestly as possible to inform parents (*Recommendation 4.3.1*). The absence of appropriately supportive data for most of the approaches underlies the reluctance that many authorities worldwide share for publicly funding specific support methods.[225, 297, 300] Furthermore non-established approaches can be costly in time and money and some have adverse effects.[298]

As autism represents a heterogeneous spectrum of conditions, supportive approaches may have differential effects on individuals, making the identification of effective supports difficult. There is a great deal of variability in response to different approaches and some individuals may show spontaneous improvement in a particular area for unidentified reasons. In such a situation, if a support has been recently implemented, the improvement may be erroneously attributed to the support, even when the approach is ineffective.

The following guidance has been suggested (which is also contained in Part 3: Education for learners – the same principles apply in both settings):[301]

- support programmes should be individually designed, taking into account the individual's cognitive level, autistic characteristics, 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 autistic person (*Recommendation 4.3.2*)

- supports should take into account the key characteristics of an autism diagnosis (e.g., communication, social skills, and repetitive and ritualistic behaviour)
- many undesirable 'behaviours of concern' reflect limited behavioural repertoires or poor communication skills, so focusing on skill enhancement and establishing of more effective communication strategies are often the most successful means of reducing difficult or disruptive behaviours (*Recommendation 4.3.2*)
- family-centred supportive 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 seems most likely to offer benefits for all involved (*Recommendation 4.3.2*).

Guidelines for evaluating different supportive approaches for autistic people/tāngata whaitakiwātanga advise parents, family, whānau and professionals to:

- ask specific questions about the support 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 approach where the efficacy has not been proven
- remember that the primary goal of any approach should be to help the autistic person/tangata whaitakiwātanga live as full a life as possible within society
- beware of any programme that claims to be effective for all autistic people/tāngata whaitakiwātanga
- be cautious of programmes that do not allow individualisation
- recognise that there are likely to be several suitable support options for each autistic person
- recognise that support choices should be based on the results of the person's individual assessment
- avoid supportive approaches that do not provide information on how to assess whether the autistic person is suitable for that support
- use appropriate methods to determine whether the supportive approach was effective (e.g., appropriate behavioural data; trialling the support for a sufficient length of time, completion of appropriate questionnaires about the targeted behaviours/skills before and after the support, telling no one when a support has started, and monitoring of the behaviour of the autistic person by making written notes)[302-304] (*Recommendation 4.3.3*).

4.3.a Behavioural approaches

Behavioural approaches, following careful and thorough functional behaviour assessment, are often the most appropriate means of addressing 'behaviours of concern' for autistic people/tāngata whaitakiwātanga[84, 283, 286, 293, 294] and those with an intellectual disability[271, 305] (*Recommendation 4.3.4*). However, the assessment must be comprehensive and consider all potential causes of 'behaviours of concern' (e.g., pain, undiagnosed medical issues, sensory problems, abuse, etc).

Although differences of opinion exist regarding how behavioural approaches are described (e.g., applied behaviour analysis, positive behaviour support, behaviour modification, behavioural programming, etc),[268, 306] and various methods of behavioural assessment and supports development have been published, all behavioural strategies/programmes are based on the science of behaviourism. It is beyond the scope of the Guideline to provide details on how a practitioner should conduct a behavioural assessment, and how behavioural programmes are developed and implemented. A large literature on this exists and includes many lengthy texts. Features common to behavioural approaches of good quality are:

- person-centred planning: through which the autistic person/tangata whaitakiwātanga remains the focus of the assessment and support 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 'behaviours of concern' (including setting, specific triggers, reinforcers) are identified, through means of thorough interview, observation, recording and/or formal testing
- positive support strategies: a preference for supports that use positive reinforcement, as opposed to punishment
- multifaceted supports: packages of support that include more than one approach, such as specific support procedures combined with staff and carer education
- focus on environment: designing or altering the environment of the autistic person to effect behaviour change
- meaningful outcomes: measures of successful supports which are significant to the autistic person/tangata whaitakiwātanga and/or the people with whom they associate
- focus on ecological validity: supports that 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 supports: strategies/programmes that take into account the systems-level issues and overall context (e.g., agency policy, staff professional learning and development, financial constraints, team values etc) and, when required, seek to alter matters at the systems level[306] (*Recommendation 4.3.5*).

Note that research on supports and strategies based on the principles of applied behaviour analysis and early intensive behavioural intervention (EIBI) in autistic children was updated as part of the Living Guideline process, is summarised in Appendix 3.1, and available as full text from Whaikaha – Ministry of Disabled People's website[15] (*Recommendations 4.3.5a and 4.3.5b, and Good Practice Points 4.3.11 and 4.3.12*). Further, the LGG prepared an important additional commentary on concerns surrounding ABA for the third edition. These are presented in Part 3, section 3.1.b.

Within Aotearoa New Zealand, a range of professionals develop and implement behavioural approaches and supports. However, there are significant variations in educational level, professional affiliation or accreditation, expertise, and supervision arrangements, all of which can impact support quality. Consumers are advised to scrutinise the expertise of professionals providing behavioural supports, including checking that the person has the appropriate professional affiliation (e.g., 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 (*Recommendation 4.3.6*). As of 2022, there are 65 certified behavioural analyst professionals in Aotearoa New Zealand, 51 of whom are Board Certified Behaviour Analysts. There are two university training programmes with verified course sequences in ABA conducted through ABAI (www.abainternational.org), and an Aotearoa New Zealand credential is being developed.[307] For further information, interested parties are referred to recently published guidelines for identifying, selecting, and evaluating behaviour analysts for autistic people/tāngata whaitakiwātanga.[308]

See *Good Practice Point 4.3.13* which provides advice on best practice for all supportive approaches.

Currently, there are no publicly funded, autism-specific, behavioural services in Aotearoa New Zealand (*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 autistic people/tāngata whaitakiwātanga, many do not. Lack of understanding of autism/takiwātanga and approaches that work effectively with autistic individuals are problems shared by many counsellors, therapists and other mental health professionals working with adults.[73, 309, 310] Knowledge and understanding of autism 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 autism, expert opinion suggests that psychodynamic styles based on insight, introspection and the development of a therapeutic alliance are unlikely to be successful[286, 311] (*Recommendation 4.3.8*). Cognitive behaviour therapy (CBT), a therapeutic approach well supported across problem areas and many different populations (including those who have intellectual disabilities), maybe more promising[111, 286, 304, 312, 313] (*Recommendation 4.3.9*). The more structured format of CBT and practical emphasis on the here-and-now may account for this.[311, 314, 315] 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 (e.g., 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.[312]

Because of the characteristics of autism/takiwātanga, even experienced cognitive behaviour therapists working with people on the autism spectrum need to understand autism 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 autistic people/tāngata whaitakiwātanga includes:

- concentrate on well-defined and specific difficulties
- attend to and intervene with the key areas of an autism diagnosis (communication, social skills, stereotypical and repetitive behaviour) and alter techniques accordingly
- minimise anxiety about the therapeutic process by being explicit about roles, times, and goals and using techniques like repertory grid

- be flexible about the length of sessions, and leaving the therapy 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[282, 311, 312, 316] (*Recommendation 4.3.10*).

Research on cognitive behaviour therapy for adults was updated as part of the Living Guideline process. It is summarised in Appendix 3.7, and is available as full text from Whaikaha – Ministry of Disabled People's website.[21] (*Also see new Recommendation 4.3.9a, and new Good Practice Points 4.3.9b and 4.3.10a*.)

4.4 Pharmacological approaches

Summary of recommendations

Recommendations:		Grade
4.4.1	SSRIs (e.g., fluoxetine) may be effective for some autistic children with high anxiety and/or obsessive compulsive 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 autistic children and young people (*see Appendix 3.2*).	B
4.4.1b	Citalopram's use for established co-occurring indications for children and young people (e.g., 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/whānau and careful ongoing monitoring (*see Appendix 3.2*).	C
4.4.2	There is insufficient evidence to make any recommendation in relation to the use of other types of antidepressants in autistic children.	I
4.4.3	Risperidone is effective in reducing aggressive behaviour, irritability, and self-injurious behaviour in autistic children. 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 uncertainly 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 Aotearoa New Zealand and all new clinical events should be reported.	B
4.4.4	In most circumstances risperidone should be the first medication used when indicated for reducing significant irritability in autistic children and young people. 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 (*see Appendix 3.2*).	B
4.4.5	Typical antipsychotics are effective in reducing motor stereotypies, aggression and self-injurious behaviour, 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 reports have implicated thioridazine in cases of sudden death. Clinicians should keep up to date with current literature.	B

Recommendations:		**Grade**
4.4.6	Methylphenidate is effective for some autistic children with co-occurring ADHD. It should be used with caution because of the high risk of adverse effects.	C
4.4.7	Melatonin can be recommended for use in autistic children and young people who are experiencing significant sleep problems (*see Appendix 3.2*).	B
4.4.7a	Benefits and adverse effects of longer-term use of melatonin require further investigation (*see Appendix 3.2*).	C
4.4.7b	Behavioural strategies (e.g., sleep hygiene) should always be used in conjunction with melatonin (*see Appendix 3.2*).	C
4.4.8	Co-occurring bipolar disorder should be managed in consultation with an appropriately experienced psychiatrist.	C
4.4.9	Autistic children who also have epilepsy should be managed in consultation with an appropriately experienced clinician.	C
4.4.10	There is insufficient evidence to make any recommendation with respect to the use of the following drugs for autism-specific characteristics in autistic children. However, these medications are in current use, and may be used by experienced clinicians, who maintain up to date knowledge of the literature: • clonidine • sedatives (benzodiazepines, antihistamines).	I
4.4.11	There is insufficient evidence to make any recommendation with respect to the use of the following drugs for autism-specific characteristics in autistic children. These medications are unlikely to be useful: • amantadine • intravenous immunoglobulins • naltrexone.	I
4.4.12	The use of the following drugs and agents is NOT recommended: • fenfluramine • secretin • chelation therapy.	 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

Supportive, educational, and behavioural approaches are the mainstay of supports. Autism/takiwātanga is not a disease so medication is not a 'cure' and environmental strategies should be the first consideration when supporting autistic individuals. However, several medications may be helpful in significantly improving various target areas and associated conditions. Many of these same medications can continue to be used in autistic adults but there is little research 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 the 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 for autistic people/tāngata whaitakiwātanga, particularly in children and adolescents. However, some evidence is accumulating for the treatment of both aspects of core autistic characteristics (largely compulsive and repetitive patterns – the 'cluster c' symptomatology of DSM IV[30]) and frequent co-occuring symptoms, including anxiety and aggression. Of necessity, therefore, many recommendations are based on short-term studies or expert opinion. Many medications used for children and adolescents on the autism spectrum 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 the numbers included in studies are small. Prescription of many agents will, by necessity, therefore be 'off-label' when applied to autistic children (that is, outside manufacturers' recommendations).[317] Parents, carers and professionals need to be aware of the implications of this practice.

In addition, the response to medications used to treat co-occurring conditions may be different for autistic children so special care is needed when prescribing in this group. For example, many children on the spectrum have co-occurring significant ADHD symptomatology. While this may often improve significantly with stimulants, stimulants may increase anxiety, sleep issues, and stereotyped behaviour. Stimulants may therefore be less useful in some autistic children. There is evidence that suggests that some autistic children become over-focused when on stimulant medication, and repetitive and obsessive compulsive behaviour may be exacerbated.[318]

Clearly, for reasons of brevity, this review cannot address the vast literature on the use of psychoactive medications in conditions other than ASD. This means that any prescriber working with autistic children 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 a separate mental health condition (e.g., ADHD), the child or person on the autism spectrum should be supported according to evidence-based practice guidelines for that condition. However, prescribers must make it clear that the treatment may not affect difficulties associated with core characteristics of autism/takiwātanga, and must ensure that there is monitoring for side effects (including worsening of areas like obsessional anxiety).

Some medications currently in use for autistic children in Aotearoa New Zealand are relatively new. Both clinicians and parents must appreciate that there is therefore very limited information on long-term safety. As children with 'behaviours of concern' 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 supplements (*see section 4.5: Other approaches*) has been studied for autistic people/tāngata whaitakiwātanga and those with related conditions, 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 several reviews by experts, although only the first of these is autism specific.[319-321]

Adults

The evidence for psychotropic medications specifically for autistic adults 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 issues), there is a lack of specialists with specific knowledge of autism.

Child and Adolescent Mental Health Services see young people until school leaving age. For Ongoing Resourcing Schemes (ORS) funded students with significant, 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 they should contact the local adult mental health service and request advice or psychiatric assessment.

Regional Dual Disability Services (i.e., 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 Living 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 about newly reported adverse effects and 'black box' warnings.

4.4.a Managing specific concerns and co-occurring conditions

The choice of drug should be guided by the clinician's assessment of the area to be targeted. Table 4.1 indicates which group of medications may be considered for a range of target concerns.

Table 4.1: Psychotropic medications used in the management of specific concerns

Core concern	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 on the autism spectrum.[313] Several open-label studies have reported positive responses to fluoxetine (Prozac) and other selective serotonin reuptake inhibitors (SSRIs). These responses include improvement in social interaction and emotional reactivity, reduction in stereotypies and obsessive compulsiveness, widening of the range of interests and improvement in the fluidity of movement. There are reports that the SSRIs may be helpful for autistic children who exhibit high anxiety (*Recommendation 4.4.1*). A Cochrane systematic review on the use of SSRIs for autistic individuals is in progress by Wheeler and colleagues at Children's Hospital at Westmead.[322] 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 Guideline.

The SSRIs as a class have several 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 the use of SSRIs in adolescents and suicidal thinking.

Note that research on the use of the SSRI citalopram for autistic children and young people was updated as part of the Living Guideline process, and is summarised in Appendix 3.2, and available as full text from Whaikaha – Ministry of Disabled People's website[16] (*Recommendations 4.4.1a and 4.4.1b*).

Heterocyclic antidepressants

Two double-blind controlled studies have been undertaken to compare clomipramine (a tricyclic antidepressant with serotonin re-uptake inhibition) with desipramine (a tricyclic antidepressant without serotonin re-uptake inhibition) and placebo.[323, 324] Clomipramine was significantly more effective in reducing obsessive-compulsive symptoms 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.[325]

In relation to the use of heterocyclic antidepressants in autistic children, 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. Several randomised controlled trials (RCTs) suggest that risperidone may be useful for children and adolescents on the autism spectrum who have serious behavioural difficulties (*Recommendation 4.4.3*). The Research Units on Paediatric Psychopharmacology Autism Network demonstrated that risperidone was effective and well tolerated for the treatment of aggression and self-injurious behaviour in children and adolescents on the autism spectrum.[326] 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.[327] 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 challenges in social interaction and communication.[328] Similarly, another study found that risperidone significantly reduced irritability and other autism-related behaviours in autistic children.[329]

While there is good evidence that risperidone is effective in reducing serious behavioural difficulties in autistic children, randomised trials and several single case reports document a number of significant potential adverse effects.[330-333] Several other atypical antipsychotic medications exist, although no RCTs relating to their use for autistic individuals 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 autistic children and young people as part of the Living Guideline process. This is summarised in Appendix 3.2, and is available as full text from Whaikaha – Ministry of Disabled People's website.[16] It is now acknowledged that risperidone should be the first medication used when indicated for significant irritability in autistic children and young people, 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
- extrapyramidal motor symptoms (e.g., 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 autistic individuals. The efficacy of haloperidol in reducing motor stereotypies, aggression and self-injurious behaviour, and improving social relatedness is not in doubt.[334, 335] However, haloperidol and the other older antipsychotic agents have a high rate of side effects, especially dyskinesias (non-typical 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.[336, 337]

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 reports have implicated thioridazine in cases of sudden death[338, 339] (*Recommendation 4.4.5*).

Stimulants

Two stimulant drugs are available for use in Aotearoa 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 autistic children were identified.[318, 327, 340, 341] The trials reported a significant improvement in ADHD-like symptoms, but no improvement in core autistic characteristics. 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. Autistic children commonly have non-typical sleep patterns.[342] One non-randomised study of 15 children diagnosed with Asperger syndrome and severe sleep problems demonstrated improvements in the sleep patterns in all cases.[343] A small controlled trial which was completed by only seven children showed improvement in sleep.[344]

Melatonin (in specific forms and brands) has been funded by Pharmac since 2017 for children on the autism spectrum who have persistent, pervasive sleep problems. Several different preparations can be purchased at retail pharmacies on the 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 autistic children and young people was updated as part of the Living Guideline process, and is summarised in Appendix 3.2, and available as full text from Whaikaha – Ministry of Disabled People's website.[16] This review concluded that melatonin can be recommended for use in autistic children and young people 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 autistic children[345] (*Recommendation 4.4.10*).

Sedatives

Benzodiazepines are sometimes used in emergencies to effect sedation and manage very disturbing behaviour. There are insufficient data to recommend this practice routinely. Benzodiazepines have the potential to cause excessive sedation and disinhibition.[346] 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 Aotearoa 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-occurring condition in children and adolescents on the autism spectrum. However, there are no controlled trials in an autistic population. No specific recommendation is made for the pharmacotherapy of co-occurring bipolar disorder. This situation should be managed in consultation with an appropriately experienced psychiatrist (*Recommendation 4.4.8*).

Antiepileptic medication

Epilepsy is relatively common in autistic children. Discussion of epilepsy management is outside the scope of this Guideline. Autistic children who also have epilepsy should be supported in consultation with an appropriately experienced clinician.

Where children with co-occurring epilepsy also require pharmacological management of ‘behaviours of concern’, prescribers must consider both potential interactions between medications AND the potential for some psychotropic medications to lower seizure threshold (e.g., fluoxetine, methylphenidate, and risperidone) (*Recommendation 4.4.9*).

4.4.b Non-established pharmacological agents

Several other pharmacological agents have been discussed in the international literature as potentially useful for modifying various autistic characteristics. 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 harmful. They are discussed here, to assist 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 Aotearoa New Zealand. The use of any of these agents to treat autistic children in Aotearoa 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 Aotearoa New Zealand for use as an antiviral agent and as an antiparkinsonian agent. One randomised controlled study was identified.[347] This study found statistically significant improvement on some subscales (notably hyperactivity) on investigator ratings, but no differences in parent ratings (*Recommendation 4.4.11*).

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.[348] The authors reported improvement in parent and teacher ratings but no difference in clinician ratings. They urged caution and recommended further research (*Recommendation 4.4.11*).

Naltrexone

Naltrexone is an opioid antagonist. It is used in Aotearoa 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 on the autism spectrum.

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.[349, 350] 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 4.4.11*).

Fenfluramine

Fenfluramine (Ponderax) was previously available in Aotearoa New Zealand for use as an anorectic in obesity. It has been withdrawn because of safety concerns. In the early 1980s, there was substantial interest in the use of fenfluramine for autistic individuals. Fenfluramine significantly lowers blood serotonin levels, which are elevated in a proportion of individuals on the autism spectrum (and other developmental conditions).

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.[351] A double-blind placebo-controlled trial was also identified.[352] 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 4.4.12*).

Secretin

There is no evidence to support the use of secretin (either human, synthetic or porcine) in autistic children. 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 characteristics 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[353, 354] (*Recommendation 4.4.12*).

Chelation therapy

There is no evidence that heavy metals are implicated in the causation of autism. There are no randomised controlled trials of chelation therapy in autistic children. Chelation therapy is potentially dangerous and, given the absence of evidence for benefit, should not be used[355] (*Recommendation 4.4.12*).

4.5 Other approaches

Summary of recommendations

Recommendations:		Grade
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 autistic characteristics in children which are unlikely to be useful for this purpose: • combined vitamin B6–Mg • dimethylglycine • gluten and casein free (GCF) diet • omega-3/long chain polyunsaturated fatty acids • auditory integration training • holding therapy • options therapy • sensory integration therapies • Irlen lenses.	I
4.5.2	The use of Facilitated Communication for autistic traits in children is not recommended.	B
4.5.2a	Music therapy can enhance social communication skills and should be considered for children and young people on the autism spectrum (*see Appendix 3.12*).	B

Over the past decades, a range of alternative approaches have been suggested to support autistic people/tāngata whaitakiwātanga. Some of these have been claimed as ‘cures’ for autism in Aotearoa New Zealand (despite cure not being a desirable goal from a neurodiversity perspective). These are being promulgated by a very small number of practitioners with little regard for the research evidence. Most of the research in this area is based on anecdotal reports rather than controlled studies. The lack of quality research evaluating these approaches means that firm conclusions cannot be drawn about their effectiveness. For a small number of treatments, there is evidence that they are ineffective and/or potentially harmful.

Addressing all possible alternative approaches, supports, strategies, programmes and therapies is beyond the scope of this Guideline. The most common alternative approaches are briefly discussed below. These include biomedical approaches and other alternative non-medical supports.

Biomedical approaches

Biomedical approaches seek to alter physiology or change the underlying processes that result in core autistic characteristics. They include combined vitamin B6–magnesium (Mg), dimethylglycine, gluten and 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 autism.[356] 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 Aotearoa 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.[357] 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 for autistic individuals, only one small trial (n=20) met the criteria for inclusion.[358] 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 reliable evidence for clinicians to advise the use of gluten-free-casein-free diets for autistic individuals (*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 approaches 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

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.[149] Music therapy has also been promoted as an effective supportive approach in facilitating communication by offering a means by which alternative communication can be established to help achieve engagement, interaction and relationships.[359]

Research on the effectiveness of music therapy for children and young people was updated as part of the Living Guideline process. It is summarised in Appendix 3.12, and is available as full text from Whaikaha – Ministry of Disabled People's website.[26] The review revealed a growing body of evidence that music therapy can provide benefits across several domains for children on the autism spectrum, particularly concerning social communication (*see Recommendation 4.5.2a*).

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 in Facilitated Communication.

There has been considerable controversy about whether the facilitated output is from the autistic person or is under the influence of the facilitator. A large number of quantitative studies show facilitator influence.[118] 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 autistic people/tāngata whaitakiwātanga. Anecdotal reports of negative side effects, such as hearing loss, have raised several ethical questions regarding its use and it has been suggested that the non-standardised and unregulated use of AIT may place individuals using this approach at risk.[360]

A Cochrane systematic review of AIT studies with several methodological flaws concluded that there is no clear evidence for auditory integration therapy nor does the procedure provide beneficial changes to behaviours of autistic people/tāngata whaitakiwātanga.[361]

The review concluded that further research is required to determine the effectiveness of sound therapies and that, in the absence of evidence, the approach must be considered experimental and parents should be made aware of the cost of approach. The American Academy of Pediatrics also suggests that the use of AIT should be limited to research protocols.[362] No recommendations can be made for this approach (*Recommendation 4.5.1*).

Holding therapy

This approach is based on the work of Tinbergen and Tinbergen[363] who erroneously claim that autism/takiwātanga is caused by an emotional imbalance that results from a lack of attachment between the mother and the autistic child, 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 approach 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 more adaptively. Sensory integration theory lacks empirical support. There are no experimentally sound studies supporting the use of sensory integration in autistic children[364] (*Recommendation 4.5.1*).

Irlen lenses

This therapy is based on the notion that autistic children 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 therapy 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 autistic students,[365] but there is no conclusive evidence of effectiveness of this approach for autism characteristics (*Recommendation 4.5.1*).

Other alternative approaches

Several other approaches have been tried. They have either not been assessed in controlled studies or studies have not found reliable evidence that they are effective. More research is required before conclusions can be reached about these therapies. These include:

- pet therapies (such as service dogs, and horse riding)
- dolphin-assisted therapy
- the Dolman-Delacato method
- horticulture
- aromatherapy.[84, 283]

4.6 Supporting people with 'behaviours of concern'

Summary of recommendations

Recommendations and Good Practice Points:		Grade
4.6.1	When 'behaviours of concern' are evident, autistic people need to be assessed for co-occurring conditions such as seizures, ADHD, anxiety disorders, depression, and gastrointestinal problems (*see Appendix 3.4*).	C
4.6.2	In harmful (to self or others) or life-threatening situations, medication may be the optimum therapy.	C
4.6.3	There should be access to interagency, multidisciplinary teams for ongoing serious behaviour needs.	✓
4.6.4	The following systems need to be in place for emergency situations and there must be a prompt response: • specialist staff with skills and experience in autism from all relevant professions available for consultancy • a multiagency team which can work in education settings and coordinate with home and community based supports • facilities to withdraw a child from class when they are, or are likely to be overloaded • 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.	✓
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 approaches (as outlined above), a small number of children, young people and adults on the autism spectrum may develop very serious or dangerous behaviours.[116] Extreme behaviours that put the autistic person, 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.[14] When 'behaviours of concern' are evident, autistic people/tāngata whaitakiwātanga may need to be assessed for co-occurring conditions such as seizures, ADHD, anxiety disorders, depression[14, 118] and gastrointestinal disorders (*Recommendation 4.6.1*). Although medications are not regarded as the treatment of choice for 'behaviours of concern', this may need to be considered for harmful (to self or others) or life-threatening situations[14, 118] (*Recommendation 4.6.2*). Behavioural approaches may enhance the use of medication[118] and expert opinion suggests that medication may enhance receptiveness to behavioural approaches.

Schools, families and whānau, and services supporting people with extreme behaviour challenges need rapid access to specialist assistance and support for staff, families and whānau (*Good Practice Point 3.2.5.5, Part 3, section 3.2.e*). A timely response may prevent the loss of current residential, educational and vocational placements.[14]

Systems that need to be in place to support a crisis response include:

- specialist staff with skills and experience in autism from all relevant professions available for consultancy
- information for autistic people, parents, family and whānau, and professionals about how to access consultancy and support from specialist staff
- a multiagency team that can work in all settings
- short break respite (with specific autism 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[14] (*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, autistic adults who exhibit 'behaviours of concern' should be referred to Adult Community Health, and, if Learning Disabled (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 on the autism spectrum 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 (e.g., transitions, staff redeployment, terminal illness of an important person), may be able to be well managed, with adequate planning, support and service provision.[366] 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 an autistic person,[56] 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 autistic people/tāngata whaitakiwātanga, 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 autistic people/tāngata whaitakiwātanga, no one system is likely to meet the needs of all people. Therefore, proactive crisis support planning should be routinely undertaken and reviewed regularly (e.g., 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 (e.g., relevant background, up-to-date medical records, communication systems, response to previous supports, personal preferences, key professional personnel) promptly
- 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 autistic people/tāngata whaitakiwātanga as mental health inpatients, alternatives to inpatient care have been recommended.[73] Crisis services have been recommended that involve staff trained in autism and that contain timely and flexible systems that can adapt to the needs of the person in crisis and minimise the need for in-patient care[73] (*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 the out-of-home placement is needed rather than in-patient facilities
- staff teams that visit autistic people/ tāngata whaitakiwātanga 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 (i.e., mental health specialists, police, probation, youth offending, lawyers)
- a training role with other relevant agencies to ensure that they are appropriately responsive to autistic people[73] (*Good Practice Point 4.7.3*).

4.8 Mental health, forensic and disability services

Summary of recommendations

Recommendations and Good Practice Points:		Grade
4.8.1	Autistic adults 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
4.8.2	People on the autism spectrum experiencing serious mental health disorders should be supported by mental health services appropriate to their age, situation and culture (*see Appendix 3.8*).	✓
4.8.3	The development of autism-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	Autistic people (with or without an additional disability) should be referred to their local Needs Assessment and Service Coordination (NASC) agency.	✓
4.8.6	Adults on the autism spectrum with intellectual disability and mental health problems should be referred to specialist Dual Diagnosis Services (learning/'intellectual' disability and mental health) through their GP or local Adult Mental Health Service.	✓
4.8.7	Autistic adults with an intellectual disability 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 autistic children and young people 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 autistic children and young people. The development of autism-specialist teams within CAMHS may be appropriate (*Good Practice Point 4.8.3*).

Autistic adults 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 autistic adults 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, autism was traditionally seen as a childhood condition, and interest in the spectrum by specialists in adult and forensic mental health is a more 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,[73, 309, 310] and across a variety of sectors (e.g., in-patient units, community services and secure services). However, no research was identified that addressed this issue. The development of autism-specialist teams within Adult and Forensic Mental Health Services and CAMHS may be appropriate (*Good Practice Point 4.8.3*).

Negative experiences of autistic adults within adult mental health and forensic systems are described in clinical settings, reviews,[286] and reports by the people themselves.[61] 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.[286] 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 autistic adults who experience mental health problems[72, 286, 310] (*Recommendation 4.8.1*). Consistency of environment and staffing may minimise stress for autistic people/tāngata whaitakiwātanga when hospitalisation in mental health services is needed on a recurring basis (*Good Practice Point 4.8.4*).

Disability services

Autistic people/tāngata whaitakiwātanga 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.

Autistic people/tāngata whaitakiwātanga 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*). Autistic people with an 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*). Autistic people 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 Part 3, section 5.3.b:Autistic people suspected, accused, charged or convicted of crimes*).

While staff working within intellectual disability services also have autism-related professional learning and development needs (*see Part 6: Professional learning and development*), a significant number of professional staff have relevant experience of autism within the population of people with an intellectual disability.

Part 5

Living in the community

“Me mahi tahi tātou mo te oranga o te katoa”

We must work together for the wellbeing of all

Part 5: Living in the community

This section of the Guideline addresses the support needs of autistic people/ tāngata whaitakiwātanga 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 and Good Practice Points:		Grade
5.1.1	Research should be undertaken to identify appropriate methods of supporting autistic people when they leave school.	C
5.1.2	Careful and timely attention should be paid to planning for autistic people leaving school and moving into further and post-compulsory education, work (paid or unpaid) or vocational services.	C
5.1.2a	Services for young people and adults on the autism spectrum should be accessible and appropriate to their ethnicity. This will require proactive strategies *(see Appendix 3.8)*.	C
5.1.3	Further and post-compulsory education should be considered as an option for all autistic people, regardless of their intellectual ability.	C
5.1.4	Planning for transition into further and post-compulsory education should consider characteristics of autism/takiwātanga 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	Tertiary education providers should work with autistic students to identify and implement accommodations that meet their learning and assessment needs. Effective approaches include offering: • extended assessment times • flexible assessment formats and testing environments • recorded lectures • lecture notes • support services staff liaison • tutoring • flexible course loads *(see Appendix 3.13)*.	B
5.1.6	Providers of further and post-compulsory education should ensure that their members of staff are aware of the specific educational and cultural needs of autistic people *(see Appendix 3.8)*.	C

Recommendations and Good Practice Points:		Grade
5.1.7	Tertiary education providers should be proactive in identifying autistic students and in implementing supports for their mental-health and wellbeing. Multi-component approaches are most effective, and include the following components *(see Appendix 3.13)*: • peer mentoring and trained professional mentoring • fostering social connection through organised, recreational activities with peers • counselling, psychological therapy and psychosocial support • problem solving, goal setting, practical life skills, and organisational skills.	B
5.1.7a	Tertiary education supports for autistic students should be easy to access flexible, individualised, culturally responsive, and mana-enhancing *(see Appendix 3.13)*.	✓
5.1.7b	Recognising that some autistic/takiwātanga students may not be formally diagnosed or do not wish to disclose their diagnosis, tertiary education providers should promote access to academic accommodations and support services *(see Appendix 3.13)*.	✓
5.1.7c	Not all autistic individuals consider themselves to be disabled. Tertiary education providers should consider using an alternative name for their student disability services that is more inclusive (e.g., Student Accessibility Service) *(see Appendix 3.13)*.	✓
5.1.8	Work (paid and unpaid) should be considered as an option for all autistic people, regardless of their intellectual ability.	B
5.1.9	Any known support needs of autistic people, including those relating to cognitive ability, should be taken into account when transitioning into any work environment (*see Appendix 3.3*).	B
5.1.10	Supported employment services for autistic people should be developed, promoted, and expanded (*see Appendix 3.3*).	C
5.1.11	Supported employment services should incorporate known features of best practice employment for people with an intellectual disability and autism/takiwātanga-specific strategies (*see Appendix 3.3*).	B
5.1.12	Any characteristics of autism/takiwātanga 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 (*see Appendix 3.3*).	B
5.1.13	Supported employment services should work with employers, managers and colleagues to maximise success in work placements (*see Appendix 3.3*).	B

Recommendations and Good Practice Points:		Grade
5.1.13a	Supported employment services are recommended and should be available for all autistic people (*see Appendix 3.3*).	B
5.1.13b	Supported employment services should make available, where required: • individualised job matching based on the person's career goals, strengths, and interests • pre-placement assessment of work tasks and work environment • 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 • 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 • job coaches with level of support is determined by need • work place modifications • long-term support in developing natural supports (e.g., upskilling managers) and, where needed, external supports (e.g., follow-up, assisting with issues which impact on work) (*see Appendix 3.3*).	B
5.1.13c	Methodologically rigorous research is greatly needed to examine and improve the effectiveness of Aotearoa New Zealand-based supported employment services for autistic people (*see Appendix 3.3*).	✓
5.1.13d	Aotearoa New Zealand based research should consider the effectiveness of supported employment services for autistic people of different ethnicities (*see Appendix 3.3*).	✓
5.1.14	Vocational services of a high standard should be available for autistic people who are not ready or able to access education or work.	B
5.1.15	Self-employment may be an appropriate option for some autistic people.	✓
5.1.16	More research is required on self-employment options for autistic people.	✓

5.1.a Leaving school

Given that restricted, stereotyped and repetitive repertoires of interests and activities are key characteristics of people on the autism spectrum, it is unsurprising that many experience significant stress when their routines are changed and their normal support systems are disrupted.[367] Leaving school alters the environment 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 autistic person/tangata whaitakiwātanga, 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), 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[367-370] (*Recommendation 5.1.2*).

Careful transition planning has been recommended to minimise the anxiety that autistic people/tāngata whaitakiwātanga and their families/whānau experience when the time comes to leave school[367-369] (*Recommendation 5.1.2*). Attention to the attachments that the autistic individual 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.[367] 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 autistic person are fully taken into account
- careful selection of a 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 (e.g., of how to manage timetables, spare time, the social demands of further education or the workplace).[73, 176, 368, 369, 371, 372]

Services for the autistic young person or adult should be accessible and appropriate to their ethnicity. This will require proactive strategies. Proactive strategies are evidenced by individuals and organisations:

- seeking advice and feedback from members of minority cultures regarding their experiences and needs
- identifying where modifications of standard approaches are required to respond to these needs

- validating these modifications in collaboration with members of the minority culture
- undertaking to ensure that culturally responsive practices and measures become integrated and standardised within their own practice, and that of the organisation they represent
- ensuring that barriers to full participation, including training and employment, of members of minority cultures within the organisation are eliminated, and replaced with strategies that enhance participation (*see Recommendation 5.1.2a*). *(Note that research on ethnic culture was updated as part of the Living Guideline process, and is summarised in Appendix 3.8, and available as full text from Whaikaha – Ministry of Disabled People's website*).[22]

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*). Improved post-compulsory education options for all disabled people is a significant action listed in the New Zealand Disability Strategy.[373] Nevertheless, people who are different sometimes experience barriers when trying to access further, post-compulsory education,[176] and, in the past, the educational options and outcomes for autistic people/tāngata whaitakiwātanga were poor.[286, 371, 374] Over the years, as autism/takiwātanga has become more readily diagnosed and better supported within schools, educational outcomes have improved.[374] Improvement may also be related to legislative changes in many parts of the world that recognise and support the rights of people with disabilities to self-determination and participation in all aspects of society.[286, 367, 373]

There is a growing awareness that universities and colleges should make themselves more supportive environments for people across a wide range of neurodiversities, cultural backgrounds, gender and sex identities, learning preferences, and mental health needs. This includes the promotion of an accessible environment that facilitates autistic students to reach their potential and flourish within tertiary education and beyond.

Autistic people/tāngata whaitakiwātanga have the right to access appropriate student services so they can complete and succeed in their tertiary education under the United Nations Convention on the Rights of Persons with Disabilities and the Tertiary Education Strategy (TES). To recognise this, from 2022, the Tertiary Education Commission (TEC)[375] requires all publicly funded providers to develop Disability Action Plans (DAPs) using the Kia Ōrite toolkit[376] to ensure they meet their responsibilities. As part of this planning, and to give effect to the new Code (Education Pastoral Care of Tertiary and International Learners) Code of Practice 2021)[377] that came into effect from 1 January 2022, tertiary education providers are required to involve learners and their communities in developing their strategic goals and plans for learners' safety and wellbeing. To meet the range of needs of autistic learners, providers should actively include the views of autistic learners.

Research on supports in tertiary education was comprehensively updated as part of the Living Guideline process and is summarised in Appendix 3.13, and available as full text from Whaikaha – Ministry of Disabled People's website[27] *(see new and revised Recommendations and Good Practice Points from 5.1.5 through 5.1.7c and Appendix 3.13*). See also the excellent guides produced by Altogether Autism for the Tertiary Education

Commission (https://www.altogetherautism.org.nz/supporting-autistic-tertiary-learners/).

Autistic people/tāngata whaitakiwātanga do have the potential to have successful and satisfying experiences in further education, regardless of their cognitive development level.[371] The chances of this are enhanced with careful planning and attention to autism-specific issues (*Recommendation 5.1.2*). Characteristics of autism/takiwātanga that may have a significant impact in further and post-compulsory educational settings, and should be considered in the planning process (*Recommendation 5.1.4*) and in delivering teaching and support services in tertiary education (*Recommendation 5.1.6*), 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 (e.g., monotonous voice, over-precise grammar and vocabulary, using complex words without fully understanding their meaning)
- literal interpretation 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 reaction to change
- poor non-verbal communication (e.g., 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-occurring mental health problems.[73]

Aspects of post-compulsory and tertiary education environments can complicate the transition into these settings, especially for autistic people/tāngata whaitakiwātanga.[72, 371, 378] 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 Aotearoa New Zealand reflect their shared responsibility to autistic people/tāngata whaitakiwātanga to maximise the chances of successful educational experiences. New Zealand universities and polytechnics have student services and accessibility support departments through which students can access a wide range of accommodations and supports to meet their learning and assessment needs (*Recommendation 5.1.5*). Information is available through the organisations' websites and some include specific autism policies.[379]

Several strategies could be considered when any autistic person/tangata whaitakiwātanga is transitioning into further and post-compulsory education, and for ongoing support. Some of them can be accessed through student service and disability support departments, but when these services are deficient, appropriate support may need to be organised from another source, which may prove hugely challenging for the autistic person.

Whilst stigma around the term disabled is being challenged and the identity increasingly embraced, not all autistic individuals consider themselves be disabled. This can be a barrier to people accessing ‘disability services’. Tertiary education providers should consider using an alternative name for their student disability services that is more inclusive (e.g., Student Accessibility Service) (*Good Practice Point 5.1.7c)*.

Support strategies include:

- vocational counselling and course selection
- buddies/guides for first-year students to help them settle in
- study skills support and development (e.g., planning and sticking to a study and assignment schedule)
- practical resources (e.g., rest and study rooms, computer access)
- multi-component approaches including peer and professional mentoring aimed at fostering social connection through organised, recreational activities with peers, as well as offering guidance in self-organisation, problem-solving, goal setting, and practical life skills
- counselling, psychological therapy and psychosocial support (e.g., dealing with the social demands of tertiary life, managing anxiety)
- 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 teaching staff of a student’s learning and wellbeing needs (without necessarily disclosing their autism diagnosis), and obtaining appropriate assistance *(Good Practice Point 5.1.7b)*
- flexible assessment formats, timeframes, and course loads
- examination adjustments and accommodations[73, 378-386] (*see Recommendations 5.1.4, 5.1.5, 5.1.6, and 5.1.7*).

One United Kingdom guideline for people diagnosed with Asperger syndrome[73] 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
- 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 disability/accessibility support staff
- progressing review of learning outcomes towards the end of the course, so that transition can be planned.

Tertiary education providers should also ensure that their teaching and support staff are aware of the wide range of educational and wellbeing needs and learning preferences of autistic students, and available accommodations and supports (*Recommendation 5.1.6*). Importantly, supports for autistic students should be easy to access, flexible, individualised, culturally responsive, and mana-enhancing (*Good Practice Point 5.1.7a*).

Expert opinion suggests that autistic people/tāngata whaitakiwātanga can experience great stress at examination time, which interferes with their ability to demonstrate the knowledge and skills they have acquired.[380] It is possible to alter examination arrangements to minimise stress and maximise performance opportunities, 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, tell 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
- allowing the student 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 autistic student
- permitting the student to have an object of comfort in the examination room
- granting extra time in advance of the examination day, as many autistic people/tāngata whaitakiwātanga find it extremely hard to work within a time limit, 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 (e.g., certain colours can be very distracting for some people, who may work better when examination papers are plain or uncoloured, though as individual preferences vary the individual should be asked)
- ensuring that instructions and questions are unambiguous, and avoid abstract ideas, except when understanding such ideas is part of the assessment
- prompting students who may have obsessive tendencies when it is time to move on to the next question, to avoid unnecessary rewriting of answers
- allowing the use of a word processor if handwriting is extremely slow

- arranging for scrutinising of answer papers by an educational professional with expertise in autism/takiwātanga 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, overly focused content of the answers and possible use of inappropriate language)[73, 380] (*Recommendation 5.1.5*).

Oral examinations can be particularly difficult for the autistic person, and for examiners, if they are unaware that the student is autistic.[380] The National Autistic Society[73, 380] 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 – the invasion of 'personal space'
- inappropriate or poor eye contact (i.e., 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 focused interest to the student
- failure to understand abstract ideas
- literal interpretation of jokes, exaggerations, and metaphors
- poor understanding of questions about relationships and social situations.

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. Autistic adults often experience difficulty securing and maintaining work. Long periods of unemployment are common, as is 'under-employment', or working below one's skills level.[61, 62, 286, 370, 387, 388] A systematic review of outcomes in adult life of 'more able' autistic people/tāngata whaitakiwātanga concluded that few specialist support systems existed for autistic adults and that most individuals relied heavily on the support of their families in finding jobs.[374] Anecdotal evidence suggests that this conclusion applies to Aotearoa 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 be autistic) found similarly disappointing results and unsatisfactory experiences.[176]

Becoming a worker is a normal life goal. For an autistic person/tangata whaitakiwātanga, whatever their ability level, becoming a worker is more likely to be achieved with careful attention to preparation and planning[369, 370, 372, 374, 387, 389-392] (*Recommendations 5.1.2 and 5.1.8*). The support needs of people with disabilities, including autism, fall into six broad areas: assistance in finding and securing 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[393] (*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.[176] However research suggests that the responsibility for 'making it work' in an employment setting tends to rest on the autistic person, rather than the employer.[394] While advice especially designed for use by autistic people/tāngata whaitakiwātanga exists,[370] strategies typically target supported employment services for autistic people.[372, 387-389, 393]

Positive work outcomes (e.g., increased chances of finding work, maintaining work and having good working relationships) for autistic people/tāngata whaitakiwātanga (including those with co-occurring intellectual disability) are more likely when supported employment services are involved[176, 372, 390-393, 395] (*Recommendation 5.1.10*). Involvement of supported employment services has also been associated with improved attitudes of employers towards autistic people, 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.[394]

Features of best practice identified in a review of intellectual disability and autism supported employment literature[372] include:

- individuals controlling their 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[372] (*Recommendation 5.1.11*).

Additional strategies recommended for use by supported employment services are:

- careful vocational assessment and job matching
- use of case management, interview 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 autistic person when deciding whether to disclose their diagnosis in the workplace
- helping employers consider the advantages of having an autistic employee (e.g., punctual, pays attention to detail, gains satisfaction from repetitive work, loyalty, stability)
- educating employers and co-workers about autism/takiwātanga
- supporting the autistic person at times of employment stress (e.g., organisational change, performance reviews)
- support in managing behavioural or emotional challenges that could hamper work performance or relationships with management or co-workers
- recognising the risk to the autistic person of discrimination, workplace intimidation and bullying, and taking appropriate steps to prevent and minimise this

- ensuring that the autistic person knows their employment rights, is a competent self-advocate and/or has access to advocacy services[73, 286, 387-389] (*Recommendations 5.1.11* and *5.1.13a*).

People diagnosed with autism and co-occurring intellectual disability can become engaged in meaningful work.[369, 389, 390, 396] Specialist schemes for assisting 'less able' autistic people/tāngata whaitakiwātanga to get into work have recorded success.[390, 391, 393] For many people with an intellectual disability, real work in real employment settings is preferable by far to vocational and day services[176] (*Recommendation 5.1.8*).

Autistic characteristics may both help and hinder finding work and obtaining employment success. For example, attention to detail may be valued highly, but may seriously hinder the speed of output. Autism/takiwātanga 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 the 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[286, 370] (*Recommendation 5.1.12*).

A strong finding in a survey of workplace supervisors of autistic people/tangata whaitakiwātanga successful in employment was that the supervisors believed that assistance from supported employment services had been crucial.[397] 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 3.3, and available as full text from Whaikaha – Ministry of Disabled People's website.[17]

No literature was accessed on self-employment options for autistic people/tāngata whaitakiwātanga. Self-employment may be an appropriate option for some autistic people (*Good Practice Point 5.1.15*) and more research on this is required (*Good Practice Point 5.1.16*).

Vocational services

All autistic people/tāngata whaitakiwātanga 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 autistic person/tangata whaitakiwātanga, especially people with significant co-occurring 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.[176] Vocational services for autistic people must be of a high standard. For further information on this area, the reader is referred to relevant sections of current Aotearoa New Zealand policy on people with disabilities.[176, 373, 395]

5.2 Recreation and leisure

Summary of recommendations

Recommendations:		Grade
5.2.1	All children and adults on the autism spectrum 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.	C
	Person-centred planning should:	
	• focus on individual choice and preference, including strengths, capacities, interests, and experiences	B
	• include recognition that autistic people have a right to privacy, a right to culturally responsive services, and a right to be autistic (*see Appendix 3.8*).	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 autistic children 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 who is autistic build up and maintain social contacts, using strategies to promote social inclusion (*See Part 3, 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 an autistic person to participate and enjoy a balance of leisure, work, self-care and other commitments[398] (*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 autistic people.[398] The project found that participating in recreation can help autistic people/tāngata whaitakiwātanga 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 several sources of information as useful for completing an assessment to identify the support that autistic people/tāngata whaitakiwātanga will need to make leisure and recreation choices. These sources included:

- verbal self-reporting
- information was 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 autistic individual 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[231] 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 sports and leisure activities may become isolated, and lonely and miss out on activities that are fun and which provide opportunities to make friends and learn new skills.[399]

Findings from three separate studies have identified several common barriers preventing participation in family and community activities, and these studies have informed both the Aotearoa New Zealand and United Kingdom governments' strategies for promoting social inclusion for people with an intellectual disability.[399-401] 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 in 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, autism researcher and author, described at the Autism New Zealand Conference 2004 how being autistic can affect an individual's ability to participate in their community.[402] In his presentation, he explained how the intense focused interests of autistic people/tāngata whaitakiwātanga 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 to access a focused interest.

However, focused interests also provided positive functions for the autistic person/tangata whaitakiwātanga 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 on the autism spectrum who lived at home found that consistent with previous research, the prevalence of friendships, peer relationships and participation in social and recreational activities were low.[403] Greater participation was predicted by:

- greater functional independence
- greater 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[404] reported that, for people with significant intellectual 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 intellectual disability.

Access to leisure facilities and meaningful activities 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 autistic individual[403] (*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 (e.g., 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 they have a sense of control and choice.

Two independent reviews of literature and health and disability services for people with intellectual disability in Aotearoa New Zealand have identified several strategies to promote community participation.[176, 400] These include:

- person-centred planning with a focus on individual abilities, including strengths, capacities, interests and experiences, and respecting the choices, culture 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 autistic people/tāngata whaitakiwātanga
- identifying and using natural (unpaid) supports
- providing formal support
- using visual supports (e.g., 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 Aotearoa 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 Autistic children

Difficulty in understanding and following social situations and cues can cause difficulties during interactions for autistic people/tāngata whaitakiwātanga. Challenges with self-initiation, motor planning and sequencing, plus a restricted repertoire of interests and play activities, mean that many autistic children have difficulty developing play skills that enable them to occupy themselves productively. Play can be one of the most difficult times for children on the spectrum: it is less structured and harder to understand because of the many social aspects to follow and involves initiation and follow-through.[398]

Many autistic children need to be taught play skills that can provide the basis for more complex social play later on. All children on the autism spectrum 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 autistic children experience difficulty transferring skills to different settings. For example, planning and communication between families and carers are important, where children and young people are provided with respite services. Any environment needs to be structured, predictable and support the function of the child in communication, personal independence and safe leisure skills[398] (*Recommendation 5.2.6*).

An autistic child is likely to need help to explore recreation options. Autistic children often display initial resistance to trying a new experience, which could be driven by a dislike of new or novel situations, or resistance to change. All children develop new interests and have preferences, and autistic children 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.[57] Jen Birch, a New Zealander who provides personal insight into her life as an autistic adult, suggests careful monitoring of the amount of recreational activity in which an individual participates and providing an adequate balance in learning, recreation, and focused interests.[180]

5.2.d Autistic young people

Autistic young people often have particular difficulties with social interaction and reciprocity. The severity of social difficulties and practical language challenges varies greatly within the autistic population, with observable behaviours including high levels of anxiety, obsessive compulsive disorders, depression, suicidal ideation, rage and defiance.[314, 405]

Adolescence marks the transition from childhood to adulthood, with the accompanying pressure to conform. Typical characteristics noted in adolescents on the autism spectrum are:

- poor communication skills
- excellent vocabulary
- focussed interests and pursuits (usually isolative) that can seem too intense for others
- a tendency to prefer predictable events, resulting in challenges around 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 consistent evidence from international research about the support strategies and services that can assist autistic young people.[73, 314, 405, 406] Autistic young people 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 autistic people/tāngata whaitakiwātanga (board games, chess clubs, drama, 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 to existing community activities, interests, clubs and leisure facilities and also to help them identify social networks (*Recommendation 5.2.7*). Some Aotearoa New Zealand schools have included leisure and recreation planning in a student's transition programme. Information in a student's transition plan must be shared with post-school providers[73] (*Recommendation 5.2.3*).

5.2.e Autistic adults

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[400] (*Recommendation 5.2.8*).

Autistic people/tāngata whaitakiwātanga 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 intense focused interests in the lives of people diagnosed with Asperger syndrome:[402]

- 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 autistic people/tāngata whaitakiwātanga, and adequate and sensitive support is required when beginning new, unfamiliar activities.[180] Support is needed to help an autistic person choose one or more sporting and recreational activities and learn the skills necessary to participate.[398]

An increasing emphasis is being placed on sport as a recreation choice.[194] While there are autistic people/tāngata whaitakiwātanga who enjoy team sports, autistic individuals and parents note that these activities require many social skills, and that team activities need to be chosen carefully.[180, 407] Individual sports (such as martial arts) may be a choice to be considered.

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.[408]

The New Zealand Department of Labour completed a project in 2004 to develop policies and practices to promote a 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.[408]

Barriers to a balanced lifestyle for autistic adults are exacerbated by higher rates of unemployment than among other citizens and barriers presented by a person's autism/takiwātanga and focused interests, which are often solitary.[400, 409] An autistic viewpoint should be considered when discussing lifestyle balance. Individuals and parents of autistic children emphasised in personal correspondence and literature that, while following personal interests do not necessarily have to isolate a person, autistic people/tāngata whaitakiwātanga do have a right to privacy and a right to be autistic[180, 410] (*Recommendation 5.2.3*).

5.3 Contact with the justice system

Summary of recommendations

Recommendations and Good Practice Points:		Grade
5.3.1	The victimisation of autistic people should be further researched.	C
5.3.2	People having regular contact with autistic children and young people should be screened for safety, and paid staff should be appropriately trained, supported and supervised.	C
5.3.3	Autistic people should be taught social skills, and be educated in sexual and community safety, strategies to keep safe when out at night, and what to do if they are abused.	C
5.3.4	If autistic people are abused, they should receive services from Oranga Tamariki, 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 autistic people 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 an autistic person 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 autistic people 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 autistic people in prison and secure settings needs further investigation.	C
5.3.9	Research is needed into how to minimise the stress experienced by autistic people when they come into contact with the police and criminal justice system.	C
5.3.10	Families and whānau, and carers of autistic people should develop good relationships with their neighbours and (where appropriate) provide them with information on autism/takiwātanga, 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 autistic person to prevent the characteristics of autism/takiwātanga developing into behaviour that leads to victimisation or criminal offending.	C

Recommendations and Good Practice Points:		Grade
5.3.12	Young people and adults on the autism spectrum 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 autistic people who come into contact with the police.	C
5.3.14	When it is known or suspected that an autistic adult 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	Autistic people involved in disputes within the Family Court are advised to seek assistance from solicitors and advocacy services with knowledge and experience in autism/takiwātanga.	C
5.3.16	Autistic people who are victims of crimes should access support from Oranga Tamariki, Victim Support, Accident Compensation Commission (ACC Sensitive Claims) and other similar agencies.	✓

5.3.a Autistic people as victims of crimes

Although it is generally accepted that autistic people/tāngata whaitakiwātanga and other disabilities have a higher likelihood of contact with the police, courts and criminal justice system than other people,[411, 412] little research on this could be found. Certainly, people with disabilities have an increased risk of being victims of crimes.[412] It is believed that autistic people/tangata whaitakiwātanga 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 to have a social contact
- dependency on others
- limited access to resources.[412]

Vulnerability to being a victim of crime may also be related to offender characteristics (e.g., personality, occupation), characteristics of the interactions between offender and victim (e.g., legitimate authority and power), social control, the environment in which the offence occurs and the culture of society (e.g., attitudes towards people who are different).[412]

The first step in prevention is good-quality care, especially when autistic people/tāngata whaitakiwātanga 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 autistic person is considered to be safe (i.e., no relevant criminal convictions, not violent), is preferably trained in understanding autism/takiwātanga, and is appropriately supported and supervised if they spend much time together with the autistic person (*Recommendation 5.3.2*). As autistic children 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[413, 414] (*Recommendations 5.3.3 and 5.3.4*).

Little research has been undertaken on the effects of abuse on people with disabilities or autism/takiwātanga, or how to reduce the effects of such stress.[415] Although a study[415] used a structured parental interview to delineate the effects of abuse from other behaviour in non-verbal autistic children who had been exposed to abuse, much more research is needed (*Recommendation 5.3.5*).

Autistic people/tāngata whaitakiwātanga need to be able to access the age-appropriate service for supporting people who are at risk or who have been victimised (e.g., Oranga Tamariki, Victim Support, Accident Compensation Commission (ACC Sensitive Claims Unit) and other similar agencies) (*Good Practice Point 5.3.16*). In cases where autistic people are unable to manage their property and personal welfare decisions and guard themselves against harm (e.g., if they have a significant 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 Aotearoa New Zealand have been developed to manage situations in which people with intellectual disability are complainants and/or witnesses in criminal cases.[416] These practices are research-based, and there is a growing international literature in this area.[417, 418] While some of this will be of relevance to autistic people/tāngata whaitakiwātanga who also have an intellectual disability, more autism-specific research is needed as the issues may be different (*Recommendation 5.3.7*). For example, in contrast to non-autistic people, autistic people/tāngata whaitakiwātanga may well be less likely to make 'false memory' errors when interviewed.[419] Furthermore, research is needed on how best to support autistic people to give evidence. For example, while facilitated communication (FC) was used to assist autistic people/tāngata whaitakiwātanga with high complex needs (minimally or non-speaking) 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.[420]

5.3.b Autistic people suspected, accused, charged, convicted of crimes

Despite some high-profile criminal cases where autistic people/tāngata whaitakiwātanga have been convicted of serious crimes, no strong evidence exists associating autism with criminal behaviour.[265, 286, 374, 421] 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.[422] However, the prevalence of autism in the prisons and secure settings is unknown;[286, 423] research is under way in Wales to explore this area further[424] (*Recommendation 5.3.8*).

It has been hypothesised that autistic people/tāngata whaitakiwātanga may be at risk of committing offences because of autism-related behavioural traits and characteristics, such as lack of empathy, lack of social understanding, the pursuit of intense focused interests, failure to recognise the implications of their behaviour, rigid adherence to rules and misuse by others.[286, 374, 425] However an alternative view is that engaging in criminal acts is due to the effect of co-occurring conditions, such as attention deficit hyperactivity disorder, depression or poor anger management.[426] Rarely does there appear to be a deliberate intention on the part of autistic people/tāngata whaitakiwātanga to hurt others.[286, 425]

Contact with police, courts and the criminal justice system is anxiety-provoking for most people, and autistic people have particular support needs. Given the nature of autism, young people and adults on the autism spectrum are likely to experience difficulties when in contact with the police, courts and criminal justice systems.[286, 411] Furthermore, common practices in these systems may inadvertently victimise autistic people/tāngata whaitakiwātanga (e.g., confrontational interviewing, incarceration with violent offenders), exacerbate their anxiety, expose them to risk (i.e., 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 autistic person (e.g., 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 autistic person to ensure that the intensely focused interests, social challenges and communication challenges of childhood do not become entrenched behaviours that expose the person to the risk of victimisation or criminally offending (*Recommendation 5.3.11*)
- establish firm and consistent rules in childhood, so that autistic people/tāngata whaitakiwātanga will accept limits on their behaviour in adulthood[286, 411, 413, 427] (*Recommendation 5.3.11*).

Advice for the autistic person/tangata whaitakiwātanga 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 are autistic or some of your autistic characteristics (it may help to have an information card on autism kept in your wallet or purse)
- ask for someone whom 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 autism and a support person present (*Recommendation 5.3.12*).

Advice for the family and whānau and support people of young people and adults on the autism spectrum, when having contact with the police and courts, includes:

- have summary information on the autistic person 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 autistic person are upheld
- seek legal services if the person is suspected of or charged with a crime
- contact specialist advocacy services as early on in the process as possible
- prepare the autistic person well for pre-court and court appearances, especially regarding the conduct of the court[73, 428] (*Recommendation 5.3.13*).

Police, courts and criminal justice personnel (e.g., lawyers, probation officers, court staff, judges and prison officers) need to know:

- how to recognise when the person they are in contact with is autistic
- the implication of autism on the behaviour of the autistic person, and his/her likely responses to the behaviour of the police, court and criminal justice personnel[411]

- strategies to ensure that the legal rights of all people concerned are upheld and that the appropriate legal processes can be followed (e.g., using an expert witness in court; recognising that autistic people/tāngata whaitakiwātanga and other developmental disabilities are vulnerable in formal interviewing conditions, whether as potential suspects or witnesses; the vulnerability of autistic people when held in custody)[286, 416, 418]
- the potential impact of minimising the seriousness of any inappropriate behaviour of a child or young person on the autism spectrum, including the potentially reinforcing effects of police being 'too nice', giving cups of tea and taking people for rides in the police car.[286]

The recommendations that autism-related 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 autism/takiwātanga may well be appropriate for Aotearoa New Zealand[73] (*Recommendation 6.15*).

The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 provides Aotearoa 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 supports. The cases of young people and adults on the autism spectrum who are charged with an imprisonable offence, and who are also suspected or known to have an intellectual disability, maybe more appropriately managed under this legislation (*Recommendation 5.3.14*).

5.3.c The Family Court

Autistic people 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 are under dispute. No information on this was available at the time of developing this Guideline. However, because of the characteristics of autism, there is a risk of significant issues in this arena, and autistic people are advised to seek legal advice from solicitors and advocacy services experienced and knowledgeable in autism/takiwātanga (*Recommendation 5.3.15*).

Part 6

Professional learning and development

> “Te manu e kai ana i te miro, nōna te ngahere; Te manu e kai ana i te mātauranga nōna te ao”
>
> The bird who eats the miro berry owns the forest, the bird that partakes of knowledge owns the world

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 that they address. Readers should refer to the cross-referencing for more information.

Recommendations:		Grade	Cross-reference
Education for assessment and diagnosis			
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 autism/ takiwātanga.	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 Aotearoa New Zealand norms have not yet been established.	C	1.2: Assessment Appendix 3.5
6.3	Norms should be developed for ASD assessment tools specifically for the Aotearoa New Zealand population.	C	1.2: Assessment Appendix 3.5
Education for planning and implementing services			
6.4	Professional learning and development curricula for people working in health, education and social services should include knowledge and awareness of particular issues that couples may experience when one or both partners is autistic.	C	2.1: Relationships
6.5	Social service staff members should have adequate education in child-welfare issues relating to parents who are autistic.	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

Recommendations:		Grade	Cross-reference
6.8	Parents, families and whānau, and staff who support autistic people 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
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 'behaviours of concern'
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 'behaviours of concern'
6.10a	Providers of further and post-compulsory education should ensure that their members of staff are aware of the specific educational and cultural needs of autistic people *(see Appendix 3.8)*.	C	5.1.b: Further (post-compulsory) education
6.11	Teacher aides, education support workers (ESW) and other paraprofessionals require professional learning and development for working with autistic 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 autistic young people 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 supports should be appropriately qualified and experienced.	C	4.3: Psychological approaches to supporting autistic people
6.15	Police, court staff, solicitors, lawyers, and criminal justice personnel should receive relevant education on autism, provided by an appropriate educational organisation.	C	5.3: Contact with the justice system

Recommendations:		Grade	Cross-reference
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 autism/takiwātanga and that their agency procedures incorporate best practice in autism.	C	4.2: Problem minimisation and avoidance
6.18	Education and supportive interventions should be planned and implemented by professionals* with appropriate autism/takiwātanga education and qualifications. ** In Aotearoa 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.*	C	3.1: Approaches to teaching and learning in the early years
6.19	Professionals (including teachers) who are responsible for autistic students 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

Recommendations:		Grade	Cross-reference
Other recommendations and Good Practice Points			
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
6.24a	Professionals working with people on the autism spectrum and their families/whānau need professional learning and development in cultural responsiveness, particularly the impact of ethnic culture on practice (*see Appendix 3.8*).	B	6: Professional learning and development
6.24b	All those who support young people and adults on the autism spectrum should be sensitive to gender and sexual diversity (*see Appendix 3.9*).	✓	6: Professional learning and development
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 appropriate recommendations from within the Autistic community.	✓	1.2: Assessment
6.27	Identification, education, and support of autism 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 strategies and 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 autistic people/tāngata whaitakiwātanga

Health

- Medical:
    - General practitioners
    - Paediatricians
    - Psychiatrists: child and adolescent; adult
    - Internal medicine specialists (or physicians)
    - All specialties
- Dental:
    - Generic
    - Specialist (e.g., 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 autistic people/tāngata whaitakiwātanga
- 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
- Autism 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
  - Oranga Tamariki
  - 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, learning support advisors, Ongoing Resourcing Schemes (ORS) funded specialist teachers, Supplementary Learning Support teachers)
- Learning support facilitators
- Tertiary organisations – disability support staff
- Lecturers who have autistic students 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 autistic people/tāngata whaitakiwātanga 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 Part 2, 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 of all aspects of professional learning and development. However, many recommendations throughout the Guideline 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 autistic people/tāngata whaitakiwātanga can improve the outcomes for those individuals if they have the necessary skills developed through appropriate education.[14, 118, 202, 224, 429]

Some general principles for professional learning and development have been developed. It is the opinion of the workstreams that these apply to all professionals, paraprofessionals and other people who provide support to autistic people/tāngata whaitakiwātanga.

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.[118] 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.[118, 212, 429]

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 the 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.[14, 429]

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 a wide range of needs. In particular, distance learning needs to be supported and developed for professionals working away from the main centres.[14]

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, practising new skills, receiving feedback, coaching, problem-solving and communicating with other team members.[14, 224]

4. Professional learning and development with a focus on autism/ takiwātanga should take place both during initial training and continue to be available throughout the working life of the professional.

Autism/takiwātanga 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 autistic person, 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.[118] Education should be provided proactively and not wait until a problem develops.[429]

Parents also require access to information, support and education as soon as concern about their child is identified[14, 429] (*see Part 2, 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.[224] 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.[224] It is important to remember that the voice of the autistic person/tangata whaitakiwātanga and their family is an essential part of any professional learning and development.[14] It is likely that these factors are also true for other groups who work with autistic people/tāngata whaitakiwātanga.

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 on the best practices in teaching and in reducing 'behaviours of concern'. 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[429] (*further information and recommendations are found in Part 2, 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 an autistic person/tangata whaitakiwātanga.[14, 118, 212, 429] 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 learning support or early intervention qualifications benefit from attending autism-specific programmes of study.[118, 202]

The content of professional learning and development programmes for all frontline service providers should include:

- knowledge of the condition and the signs of autism/takiwātanga at various ages (*see Part 1: Diagnosis and initial assessment*)
- knowledge on how to adapt the New Zealand Curriculum, especially for autistic/takiwātanga learners with impacting co-occurring conditions on learning
- skills in interacting and communicating with autistic people/tāngata whaitakiwātanga and their families and whānau and wider support network
- the voice of the consumer (first-hand experience of autism/takiwātanga)
- parent involvement (family/whānau views and values)
- theoretical underpinning of instructional approaches
- the development of skills 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 'behaviours of concern'
- skills in supervision and management of paraprofessionals, organisation,- and collaboration with other team members.[14, 118, 429]

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
- techniques for addressing 'behaviours of concern' for this particular person
- instructional methods for the development of new skills
- optimum arrangement of the environment.

Every adult working with an autistic person/tangata whaitakiwātanga 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 (e.g., Picture Exchange Communication System (PECS) or Incidental Teaching).[224, 430] Paraprofessionals and in-home carers need to be trained in strategies such as naturalistic teaching, visual supports, communication and social skill methods, as required.[429] An Aotearoa 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 teaching or caretaking.[431]

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 the role and who will provide supervision.[118] It is not appropriate for paraprofessionals to have sole responsibility for implementing or decision-making about supports or programmes.[224]

Teams

Because autistic students 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 management strategies for 'problem' behaviour ('behaviours of concern').[118, 224] It is helpful if the team approach is reflected in the style of professional learning and development and that different professionals are allowed to share learning opportunities.[118] 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 autistic people/tāngata whaitakiwātanga to have access to adequate support from specialists.[14, 118] Staff who operate in a specialist role or who train others will need additional education.[130, 202, 224] The skills of those who provide education and support to others should be considered as the priority in a national professional learning and development plan.[14, 118]

As well as education in their professional area, specialists such as therapists, psychologists, specialist teachers and relevant medical consultants need advanced autism-specific professional learning and development. They also require access to information networks and autism-specific consultancy services. Professional learning and development in cultural awareness are particularly important.

Frontline staff require an opportunity to participate in hands-on education and ongoing mentoring, peer review and supervision from specialist staff.[118, 130] Such specialist professionals need to understand a variety of approaches and techniques and be able to communicate with and educate other staff.[118, 429] 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 autistic person.[130, 202]

Consultants

Identification and development of consultants from each profession who will be available to support specialists and provide second opinions should be a priority.[14, 118, 429] Nominated people should be available to provide consultancy and professional learning and development to specialist staff.[14] 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.[118, 429]

Awareness in other professional groups

Many other professionals are not involved in direct services to autistic people/tāngata whaitakiwātanga. On occasion, these professionals may be required to interact directly with autistic people/tāngata whaitakiwātanga 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 that autistic people/tāngata whaitakiwātanga 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.

7. Professional learning and development should be offered in cultural responsiveness.

Professionals working with people on the autism spectrum and their families/whānau need professional learning and development in cultural responsiveness, particularly the impact of ethnic culture on practice (*see Recommendation 6.24a, and Appendix 3.8 relating to the update on ethnicity undertaken through the Living Guideline process*[22]).

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 autistic children. It is the opinion of the Guideline Development Team that the following aspects of the structure are relevant for all sectors which serve autistic people/tāngata whaitakiwātanga in Aotearoa New Zealand:

- a national plan for personnel preparation around autism/takiwātanga across all sectors
- assistance for professionals in the form of support and ongoing professional learning and development
- development of tools for autism/takiwātanga programme evaluation
- development of a communication network for professionals working in the area of autism/takiwātanga
- development of demonstration programmes where professionals can observe and learn new skills
- development of a data system that 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 autism/takiwātanga.

There is a need for professional learning and development to be coordinated nationally and for standards for professional learning and development to be developed.[14, 118]

Part 7

Māori perspectives

“Ehara taku toa i te toa takitahi, engari he toa takitini”

I come not with my own strengths but bring with me the gifts, talents and strengths of my family, tribe, and ancestors

Part 7: Māori perspectives

Summary of recommendations

Good Practice Points:		
7.1	Information packages in relevant and appropriate language about takiwātanga, health, education and disability services should be developed. In plain and simple language, the packages could include the following: • current knowledge of takiwātanga across the continuum • inventory of autistic characteristics across age groups • dual diagnosis and differential diagnosis information • availability of specific health, education, and disability services by region • funding avenues across health, education, and disability services • recommendations on harm and safety issues • helplines by region • respite care information • reliable autism/takiwātanga (international and national) internet sites • pictorial information • multimedia resources (e.g., video).	✓
7.2	Autism/takiwātanga 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: • iwi organisations, rūnanga, marae • urban Māori authorities • professional organisations across Māori health, education and disabilities fields • mainstream television screening Māori programmes (e.g., Marae) • Māori television • radio • libraries • all takiwātanga support groups and networks • police and law enforcement agencies • Mental Health Foundation website • road shows and workshops.	✓
7.3	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 takiwātanga.	✓

Good Practice Points:		
7.4	A takiwātanga antidiscrimination and destigmatisation campaign should be developed.	✓
7.5	A programme of empirical research that would provide baseline information about Māori and takiwātanga should be developed.	✓
7.6	Takiwātanga provisions for Māori tamariki, rangatahi, pakeke and their whānau should be culturally appropriate. This involves valuing and affirming their cultural identity by including Māori concepts, knowledge, skills, reo, processes, practices, resources, customs, attitudes, values and beliefs.	✓
7.7	Provisions for tāngata whaitakiwātanga should align with Māori concepts of takiwātanga, Māori worldviews, be whānau-focused and holistic in nature.	✓
7.8	Diagnostic assessment of tāngata whaitakiwātanga should utilise culturally appropriate, relevant assessment measures and procedures and be conducted in an environment where they and their whānau feel culturally safe and supported.	✓
7.9	Culturally appropriate provisions should be readily available and accessible. If needed proactive measures should be taken to overcome barriers to accessibility such as rural location, financial hardship, family circumstances, 'red tape', jargon, cultural bias, stereotyping, and other factors that can adversely affect accessibility.	✓
7.10	People who work with tāngata whaitakiwātanga should possess the knowledge, skills, and attitudes needed to provide culturally responsive, friendly, and effective services. This includes valuing and supporting Māoritanga and Māori expertise.	✓
7.11	The core curriculum of initial, in-service, and on-going professional training should include content to develop the cultural competence needed to work successfully with tāngata whaitakiwātanga and their whānau.	✓
7.12	Proactive measures should be taken to upskill people who lack cultural competence and are currently employed in services for tāngata whaitakiwātanga.	✓
7.13	Proactive measures should be taken to increase the number of Māori working with tāngata whaitakiwātanga in general and to increase and support kaupapa Māori provisions for tāngata whaitakiwātanga.	✓
7.14	Parents, whānau and, where appropriate, tāngata whaitakiwātanga themselves, should be consulted on an on-going basis and involved in all goal setting and decision-making relating them. This includes consultation about their needs and aspirations; areas of importance and concern; relevance and appropriateness of provisions and the nature and extent of cultural input preferred and involvement possible.	✓

Good Practice Points:		
7.15	Professionals should develop a collaborative relationship with parents and whānau. This includes listening to and being guided by parents and whānau, advising on their entitlements and supporting them to access resources and services, especially during transition periods such as beginning, changing, or leaving school. Parental and whānau interaction with professionals should be an empowering experience where professionals are assisted to incorporate cultural content and parents and whānau are provided with the skills, knowledge, opportunity, and authority to act for themselves and make their own decisions.	✓
7.16	Takiwātanga-focused policies, reports, research, resource development and data collection should all include a Māori component.	✓

This part of the Guideline comprises two sections. The first section describes the methodology used to identify evidence-based information relevant to Māori and takiwātanga 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 takiwātanga. The second section outlines the background of several hui held throughout Aotearoa New Zealand on the topic of takiwātanga 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 takiwātanga. Good Practice Points 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 takiwātanga, 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 takiwātanga.

Despite providing a rich source of guidance around Māori perspectives, there were concerns that Part 7 of the original Guideline only included three Good Practice Points (GPP) specifically relating to Māori.[432]

For this (third) edition, expert consultant Associate Professor Jill Bevan-Brown (Massey University, retired) developed 11 additional Good Practice Points. These were derived from evidence identified by the original literature review and hui and aim to give Māori perspectives greater prominence.

The new GPP are numbered 7.6 to 7.15 to reflect they're being associated with evidence included in the original Guideline, rather than new evidence considered through the Living Guideline process.

Good Practice Points 7.6 to 7.9 relate to Services/Programmes/Supports/ Assessment. Good Practice Points 7.10 to 7.13 concern Personnel with bicultural and bilingual expertise. Good Practice Points 7.14 and 7.15 refer to parents and whānau. And Good Practice Point 7.16 is about administration/documentation.

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 takiwātanga.

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 Aotearoa New Zealand context were also taken note of in the 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 (i.e., 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 group 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 (IN NZ) Online. E-journals specifically relevant to autism 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 autism (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 support issues involving ASD/autism 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 takiwātanga. For this part of the 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 takiwātanga.[129] 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 autistic tamariki and rangatahi. The purpose of Bevan-Brown's study was to enable the family to tell their own stories regarding their experience of caring for autistic tamariki Māori.

A synopsis of the findings raised in this seminal report included the issue of delayed diagnosis, a limited understanding of takiwātanga 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 takiwātanga 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 the first diagnosis through to the subsequent supports for autistic tamariki and rangatahi.

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 assertions or referred to contextual factors inordinately different from those of Aotearoa New Zealand. For these reasons, they were discounted as being able to inform this review on Māori and takiwātanga in a credible way.

The first paper by Shek and colleagues involved the validation of a Chinese version of the PEP-R scale.[433] Their findings supported the cross-cultural validation of this tool. They recommended that their study be replicated in the Western context by 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' decisions about supports for their autistic tamariki.[434] The main foci of the paper include developing a more informed understanding of how families interpret autistic characteristics and, as a consequence, how these interpretations shape beliefs about causes of takiwātanga 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 support decisions involving autistic tamariki. Importantly, within this paper, several significant issues are raised. These issues, however, largely refer to what is not known about the association between takiwātanga 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 characteristics of takiwātanga or known divergence across cultures regarding the relationship between aetiological beliefs held about takiwātanga by families and subsequent support decisions. Whether delays in service seeking or preference for alternative approaches correspond with specific cultures' lay beliefs about causation is not known relative to takiwātanga. 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 the representation of ethnic minorities with takiwātanga. This may arise because of differential attitudes being directed to members of these groups by professionals from the first presentation of characteristics of takiwātanga through to choices of supports for takiwātanga.

Access issues are also commented on by Mandell and Novak. In this regard, they suggest that the geographical location of families bears more influence on tamariki with characteristics of takiwātanga 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 concerning takiwātanga is seldom to treat the condition, but rather to address challenges associated with it. They recommend research be undertaken to unravel the hypothesised relationship between culture and takiwātanga. In their view, such research would include: identifying whether any cultural differences exist in the presentation of takiwātanga; how families interpret takiwātanga characteristics and respond relative to help-seeking and support 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.

More recently, research on the impact of ethnicity on the recognition, diagnosis, education, mental health approaches, and support services for tāngata whaitakiwātanga, and their family and whānau, was updated as part of the Living Guideline process. This update led to the revision of current and the development of new recommendations and Good Practice Points. It is summarised in Appendix 3.8, and is available as full text from Whaikaha – Ministry of Disabled People's website.[22]

Unfortunately, since the studies of Bevan-Brown (2004) and Mandell and Novak (2005), research focused on Māori with autism/takiwātanga has been limited. However, Professor Bevan-Brown considered a recent literature review by Riwai-Couch (2021)[52] and notes that this research is consistent with the Good Practice Points outlined at the beginning of this chapter.

The following section reports on several hui held nationwide that were undertaken on the subject of takiwātanga and Māori. As is described, these hui were organised to extend the opportunity for Māori to contribute their views and perspectives about takiwātanga.

7.2 National hui

This section reports on information gathered from five hui that were conducted throughout Aotearoa 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 instead of empirical evidence that reports directly on Māori and takiwātanga, an important caveat needs to be made about the information reported in this section. The information that follows represents subjective opinions and views regarding takiwātanga 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 takiwātanga, 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 takiwātanga. It is anticipated that the content of this section will provide a significant foundation from which future research examining Māori and takiwātanga will draw and build.

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, several questions were developed. Along with these questions, background information about takiwātanga 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 takiwātanga. 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 a 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 takiwātanga related issues – open discussion.

Invitations were extended to all interested individuals using several 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, Learning Support, Child, Youth, and Family (now Oranga Tamariki), kaupapa Māori services, takiwātanga 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 takiwātanga 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 tāngata whaitakiwātanga Māori

1. There appear to be low numbers of Māori receiving takiwātanga-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 takiwātanga
- lack of culturally appropriate professionals, services, and contexts
- funding and resource constraints
- lack of information available for whānau
- reluctance or a delay in seeking support
- uniqueness of takiwātanga.

Attendees to the hui identified geographic, economic, cultural, information and individual factors as to why it has been speculated that autistic tamariki Māori and rangatahi Māori appear to be under-represented.

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 worldview, Māori frameworks of health such as Te Whare Tapa Whā,[43] and the inclusion of Māori processes during assessment and diagnosis procedures. Whānau involvement and empowerment were also emphasised. Participants voiced the view that the 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, support 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, Learning Support), 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 tamariki
- reluctance or delay in seeking support
- 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 wairuatanga, for professionals to be familiar with Māori world views, models of health and protocols, and the value of involving holistic approaches and tohunga in the provision of care. The concept of whakamā was also mentioned as a possible impediment that may influence delays in support seeking by parents or carers.

An observation was recorded involving the length of time it takes to receive accurate professional advice from the first observation of concern 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 the availability of services, were also noted.

4. Are these problems made harder because te tangata whaitakiwātanga 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 te tangata whaitakiwātanga is Māori, responses fell into four categories. These were:

- geographic isolation (access difficulties and isolation)
- reluctance or delay in seeking support
- 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 in assessment and diagnosis was when an individual received a diagnosis of takiwātanga 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 tāngata whaitakiwātanga Māori and their whānau to do so within a holistic frame of reference. The main issue raised was for professionals to consider also the wairua and emotional aspects of an individual being diagnosed with takiwātanga 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 an 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 takiwātanga, transparency of approach and the elimination of labelling relative to takiwātanga.

6. What would be the most important features of an effective assessment and diagnosis service for autistic tamariki Māori or pakeke Māori?

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 takiwātanga, 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 takiwātanga 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 is 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 several 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 tāngata whaitakiwātanga Māori 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 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 takiwātanga 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 the tangata whaitakiwātanga.

9. Identify any Māori-specific issues or needs during post-diagnosis support.

The responses to this question included there is a lack of continuity in service provision from a diagnosis of takiwātanga and therapy, and a need to consider a grieving period for Māori on receipt of their tamaiti or whānau member receiving a diagnosis of takiwātanga. 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 tāngata whaitakiwātanga Māori and their whānau.

Kaiarahi

10. The need for a kaiarahi (guide) was identified in the development of the background information for the takiwātanga 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 takiwātanga-related services?

Responses to these questions are grouped into 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 takiwātanga 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 autistic son or daughter?

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 favoured the opportunity to more fully participate in educational decision-making. Involvement of the whānau was emphasised as were being given a range of options about educational services available to their tamaiti. It was noted that this information should be provided to the parent, carer and whānau as soon as possible from the point of the first diagnosis. A more streamlined approach was called for across the various educational programmes and services to facilitate continuity and consistency of education for autistic tamariki. This was deemed particularly important, as transitions across different educational environments and their success (or otherwise) can lead to stressful times for the tamaiti 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) and other support plans to be undertaken was also noted, as was the requirement that the cultural choices of whānau for their autistic members 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 takiwātanga (i.e., with higher and more complex support needs) and not the same level of support given to 'less severe' cases (i.e., with less obvious support needs). Regarding environmental factors, it was suggested that some schools are 'learning needs phobic', they continue to be monocultural in both tone and practice, and 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 the 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 the education of their tamaiti.

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 to 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 the 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 was 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 supports with their autistic tamariki, 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 supports.

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 supports 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 supports. Concerning the latter point, a process was suggested whereby the kaiarahi, service provider, whānau and tangata whaitakiwātanga 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 a takiwātanga 0800 support or text line where information from a Māori perspective was provided, including information about supportive approaches 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 tamaiti 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 autistic tamaiti Māori 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 the stigma surrounding the thoughts and myths attached to takiwātanga.

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 tamaiti 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 tamaiti 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 wairuatanga of the autistic tamaiti about their world view was also posited as a cultural consideration.

Services and ongoing support

16. Tāngata whaitakiwātanga use a wide range of services within the disability sector. What are some of the barriers to 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 tamariki
- reluctance or delay in seeking support.

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 tamariki and rangatahi 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 autistic tamariki with higher/more complex supports needs and those who have fewer support needs. 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 takiwātanga services. It was also noted that late diagnosis of takiwātanga 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 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 tamaiti has received a diagnosis of takiwātanga. 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 made available to Māori about takiwātanga was also mentioned. Two examples that illustrate this gap in services are pakeke leaving home before receiving a diagnosis and tamariki not receiving teacher aide support in regular schools. More support information was required that described whom 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 takiwātanga 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 takiwātanga 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 takiwātanga could be developed, which might strengthen awareness and understanding of takiwātanga 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 takiwātanga. It was proposed that such a campaign could draw usefully from the 'Like minds, like mine' destigmatisation of mental health programme. Positive messages about takiwātanga could be specifically directed toward raising awareness of takiwātanga in a public forum and reaching 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 autistic tamariki, rangatahi and pakeke Māori?

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 tamariki Māori as occurring with changes from early childhood education services to the 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 autistic tamariki 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 autistic tamariki and rangatahi in the school environment may be considered a burden by teachers who may not be sufficiently skilled to meet the support needs for these tamariki in the educational environment.

Regarding the transition from school to work, participants suggested that there is a gap in teaching appropriate life skills to autistic rangatahi 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 approaches. Advocacy services provided by iwi organisations and Māori providers also needed more attention such as developing services appropriate for tāngata whaitakiwātanga and their whānau. Relative to funding, participants suggested that regular reviews of resource allocation for takiwātanga should be undertaken. Such reviews would involve identifying whether adequate resources were being provided to the takiwātanga 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 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 takiwātanga, cultural training, and funding information. Other workshops might involve education for professionals and employers who work with tāngata whaitakiwātanga and their whānau. A feature of such workshops would be to destigmatise takiwātanga and challenge negative stereotypes about the condition.

19. Respite is a theme in the background information for the takiwātanga hui. What are some of the most important features of an effective respite service for autistic tamariki or pakeke Māori?

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 takiwātanga. 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 a 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 takiwātanga, 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 takiwātanga 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 takiwātanga information in te reo Māori
- develop a mainstream information package. This would contain different strategies for managing 'behaviours of concern' so that services could provide adequate support to tāngata whaitakiwātanga
- to develop a Māori information package. This would describe what takiwātanga is and what it means
- to 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 takiwātanga. It was noted that for some Māori, a pause is needed after a diagnosis of takiwātanga has been received so that they have sufficient time to grieve. Providing a lot of information immediately after a diagnosis of takiwātanga 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 of their autistic family member was also mentioned.

21. How could takiwātanga-related information be made more accessible and more useful to Māori?

Several different responses were provided to this question. These included:

- development of a video featuring kaumātua who could describe the issues involving takiwātanga. 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 takiwātanga information through the media (e.g., television, radio) with well-known personalities and presenters delivering the information
- provision of workshops presenting a range of information about takiwātanga assessment and diagnosis, post-diagnosis support, education, and disabilities support.

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 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 Guideline?

All responses to this question positively endorsed the inclusion of a chapter (Part) 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 tāngata whaitakiwātanga Māori, and that the Ministries involved in this project had an obligation under Te Tiriti o Waitangi to include such information.

Open-ended discussion

23. Are there any other takiwātanga - 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 about the health system's inability to understand Māori needs, rather than using a blaming Māori approach
- the need for takiwātanga hui that are more inclusive of parents and whānau
- Māori communities need to ask themselves what support they offer to tāngata whaitakiwātanga Māori. 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 takiwātanga or similar types of conditions are often seen as normal and life reflects that. Kawa and tikanga can accommodate autistic whānau
- questions about the funding for the 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 takiwātanga including:
  - their age
  - whether they are Māori or non-Māori
  - their takiwātanga
  - them as an individual
- autistic tamariki Māori are seen as a gift and embraced in whānau
- information from the hui should go to the policymakers.

Part 8

Pacific Peoples' perspective

> “Fakamalolo ke he tau amaamanakiaga, ke mafola ai e tau matakainaga”
>
> Strengthen all endeavours and the community will benefit *(Niuean proverb)*

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 autism.	✓
8.2	Appropriate educational material in language appropriate to each specific Pacific Island group should be provided to enhance understanding of autism and support services they may be eligible for.	✓
8.3	Pacific People’s support workers, carers, teacher aides, cultural workers and/or clinicians should be involved from the point of assessment and diagnosis through to coordination and support.	✓
8.4	The establishment of Pacific community support networks specific to autism in appropriate geographical locations should be facilitated.	✓
8.5	Services must be proactive in offering supports.	✓
8.6	Decision-making regarding assessment, supports 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 autism and Pacific people should be developed.	✓
8.8	A targeted recruitment and development strategy to support increasing the capacity and capability of the Pacific autism-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 People’s cultural values and world views and appropriately apply this to their work.	✓

There is no robust formal research to date that addresses issues of autism in Pacific populations yet anecdotal evidence, expert opinion and qualitative reports identify that autism 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.[435]

The Pacific Health and Disability Action Plan[436] sets out the strategic direction and actions for improving health outcomes for Pacific Peoples and reducing inequalities between Pacific and non-Pacific Peoples. Promoting the 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 Aotearoa New Zealand's total population is of Pacific ethnicity (or 265,974 people).[437] 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 Aotearoa New Zealand with about two-thirds of the population located in the Auckland region.[437] 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 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.[438] 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 autism in a Pacific population and, in line with mainstream epidemiological research, the incidence and prevalence of ASD in the Pacific population within Aotearoa New Zealand is unknown. Research on general disability and Pacific people living in Aotearoa 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 Aotearoa New Zealand.[439]

The recommendations contained in this section are derived from public reports, guidelines and published statistics and consultation through a fono.

8.1 Pacific Peoples' concepts of health

Common values across Pacific nations are ideals such as respect, reciprocity, communalism, collective responsibility, humility, love, service and spirituality.[440] 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 aunties, 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.[441] 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.[442] One contributing factor is thought to be the high degree of stigma attached to disability in Pacific cultures so that the presence of a disability is seen as shaming for the family.[151] 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, about 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[151] and, as regards autism, may prevent significant difficulties from being identified early.[150] Furthermore, the guilt and shame associated with an inability (or perceived unwillingness) to bear the full burden of care increase the chances that services may not be accessed.

Qualitative information suggests that autism may not be understood 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 autistic child may 'grow out of it', or may be seen as just 'a naughty child'.[150] 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'.[150]

8.2 Considerations when dealing with autistic Pacific people

- 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 about autism before carrying out an assessment and incorporating this into the support plan.
- Provide appropriate education for Pacific families who may be vulnerable to misunderstanding autism and autism services. Material written in English is not culturally appropriate for Pacific Peoples with their oral tradition and understanding the messages requires too high a proficiency in written English.[151] All written material should be produced in Pacific languages as well as in oral form (e.g., 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 support. 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 autism-specific knowledge.
- Facilitate the establishment of more Pacific community support networks specific to autism in appropriate geographical locations. Currently there are just two Pasifika Autism Support Groups (PASG) one in Wellington and one in Auckland: http://www.asdpasifika.org.nz/
- Provide proactive support 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 about the characteristics of autism. Any decision-making regarding assessment, support 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 autism and Pacific Peoples, the contents of this chapter merely symbolise a starting point for the Pacific Autistic community and sector.

Robust research investigating autism in the Pacific population is urgently needed, particularly epidemiological information identifying the prevalence and extent of autism occurring in the Pacific population. Qualitative information is also required to gain a deeper understanding and knowledge of the presentation and nature of autism 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 Guideline recommends involving Pacific people in the assessment and support 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 autism-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 Peoples. 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 more appropriately and effectively.

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 support and ultimately better outcomes for Pacific autistic people and their families.

Glossary

“E koekoe te tūī, e ketekete te kākā, e kūkū te kereru”

The *tūī* chatters, the parrot gabbles, the wood pigeon coos

Glossary

Glossary of terms and abbreviations

Accident Compensation Corporation (ACC)	Accident Compensation Corporation
Accommodations	Adaptations that remove barriers to enable equal participation. These are based on the premise that students with disabilities should be neither disadvantaged nor advantaged relative to other students. Students can be treated differently if it is achieving equity.
Adaptations	changes to accommodate the student's needs or preferences
Adaptive behaviour/skills	an individual's ability to act appropriately in social situations and to take care of their personal needs
Adult-directed	the adult decides on the goals, materials and teaching strategies and gives instructions (usually without consideration of child preference)
Advocacy	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.
Aetiology	study of the causes of diseases or disorders
Age-appropriate	activities, materials, curriculum, and environment consistent with the chronological age of the child
Agranulocytosis	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
Aided symbol use	see augmentative communication
Akathisia	a movement disorder characterised by restlessness and an inability to sit or stand still
Animal therapy	contact with animals (e.g., riding horses, swimming with dolphins) as therapy
Anorectic	lacking in appetite

Anorexia	lacking in appetite. The term is most commonly used with respect to eating and the disorder anorexia nervosa.
Anorexia nervosa	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
Applied behaviour analysis (ABA)	the Living Guideline Group provided this definition following their update on applied behaviour analysis.[15] 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 strategies designed to decrease negative (or 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). Strategies designed to increase positive behaviours (e.g., 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 (e.g., family, culture), and the likelihood that the new behaviour will result in positive natural consequences. For programmes 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. It has become quite common for highly structured, intensive early invention programmes to be called 'ABA' however this is not correct, since ABA refers to a wide variety of techniques and principles.

Arrhythmia	an abnormality of the normal heart rhythm
Art therapy	art as non-verbal, symbolic means for an autistic person to express him/herself
Asperger syndrome (AS)	a subtype of autism spectrum disorder where individuals do not have significant delay in structural aspects of language and cognitive development (this diagnosis has been removed from DSM-5)
Assistive technology (AT)	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.
Attention deficit hyperactivity disorder (ADHD)	a disorder of attention to task, characterised by difficulty completing tasks in all settings, and often associated with hyperactive behaviour
Audiologist	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.
Audiology	the assessment of hearing loss and disorders. Also the study of hearing disorders.
Auditory integration training (AIT)	an auditory technique which works on the concept that hypersensitivities and processing abilities can be remediated by modulated/filtered music provided through earphones
Auditory processing	processing information which is received aurally
Augmentative and alternative communication (AAC)	frequently simply referred to as augmentative communication (AC). Compensating for challenges in individuals with expressive communication disorders. It might include supporting or developing communication with sign language, visual symbols, or voice output devices.

Autism spectrum disorder (ASD)	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[29] all people who are diagnosed with ASD share characteristics in two domains: challenges in social communication or social reciprocity, and restricted, repetitive patterns of behaviour. Although these features are characteristic of all autistic people/tāngata whaitakiwātanga, it is a very heterogeneous condition affecting a very diverse group of individuals with a wide range of support needs, disability and intellectual function.
Autism	characterised by challenges in communication, social and restricted interests, activities and behaviours. May include intellectual disability.
Aversive measures/procedures	behavioural methods employing punishment or the withdrawal of privileges, rather than positive reinforcement
Backward chaining	steps to performing a task are identified – the last step is taught first and this process is continued until all the steps are learned
Behaviour	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. 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.
Behaviour analysis	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).
Behaviour management	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

‘Behaviours of concern’	behaviours people do that may be a problem for themselves or others. These behaviours can include hurting themselves, hurting others, breaking things, refusing to do things, doing the same thing over and over, doing things others don’t like (e.g., screaming, taking off clothes), or hiding away. This behaviour can stop them from doing things that other people do, like going to school or seeing their friends. The behaviours can seriously hurt people. They can be very stressful and upsetting. Behaviours of concern are sometimes called ‘challenging behaviours’ or ‘problem behaviours’. It is important to remember that it is the behaviour that is the problem, not the person. Behaviours happen for a reason and the person may need support to address their needs.
Biomedical	an umbrella term for those approaches which have a medical, biochemical, or dietary basis, but are not pharmacological
Bipolar disorder	a major affective disorder in which both manic and depressive episodes occur
Body language	communication that occurs as a result of using gestures, posture etc
Capacity building	to improve organisational ability/capacity to respond to a particular need, or meet a demand
Cardiotoxicity	having a direct toxic or adverse effect on the heart
Caries	tooth decay, cavities
Cartooning	use of cartoons to enhance social understanding, for example, by drawing thought bubbles to show what someone is thinking
Chelation	administration of a chemical compound to bind a metal so that the metal can be eliminated from the body
Child, Adolescent and Family Services (CAFS)	mental health services for children and adolescents. Also referred to as Child and Adolescent Mental Health Services.
Children and Adolescents Mental Health Statewide Network (CAMHSNET)	Children and Adolescents Mental Health Statewide Network
Child-centred	the goals, materials and teaching strategies are determined with consideration of the child’s interests and preferences
Child-led	the activities follow the child’s lead or interest
Circle of Friends	a programme for developing a support group of peers around the child

Co-occurring condition	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 is autistic might also develop leukaemia. That the autistic child complicates treating the leukaemia, but the two conditions are independent of each other.
Cognition	general term for the processes involved in thinking
Cognitive assessment	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.
Cognitive behaviour therapy (CBT)	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.
Cognitive behaviour modification	see cognitive behaviour therapy
Cognitive learning strategies	technique used in cognitive behaviour therapy
Cognitive scripts	technique used in cognitive behaviour therapy
Collaborative consultation	a problem solving process that reflects high levels of communication and coordination
Communication partner	the receiver of the message in a communicative exchange
Communication	the act of exchanging or expressing thoughts, feelings and ideas
Complex Communication Needs (CNN)	a person with complex communication needs is unable to consistently rely on speech to meet all of their functional communication requirements. For some people this is temporary, while for others it is ongoing. Complex communication needs may be associated with developmental or acquired disabilities.

Consultative model	an integrated process of service provision where the professional works with others (e.g., classroom teacher and teacher aide) to achieve outcomes for the child, school or family
Contemporary applied behaviour analysis	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
Cooperative teaching/learning	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
Core characteristics	the core features of autism defined in diagnostic criteria
Cue dependent responding	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
Culturally responsive	to recognise, reflect and validate a person's history, cultures, and worldviews.
Curriculum modification	modifications or alterations to the content, strategies, mode of delivery, and/or expectations to accommodate the needs of the individual
Daily life therapy	see Higashi Schools therapy
Denver Health Sciences Programme	developmentally based programme employing behavioural techniques
Desirable Objectives and Practices (DOPs)	Ministry of Education policy documents for early childhood education services
Developmental coordination disorder	difficulty in the planning and execution of purposeful movements that result in difficulty performing fine and gross motor skills (e.g., drawing, buttoning, dressing, learning new motor skills and speech etc). Also known as dyspraxia.
Developmental delay	a delay in one or more areas of language, cognition, motor skills, or other adaptive behaviours
Developmental, Individual Difference, Relationship-based Model (DIR)	type of developmental intervention
Developmental paediatrician	a paediatrician who specialises in the assessment and care of children who have developmental problems or disability

Developmental programmes	programmes which are guided by considerations for the sequence in which children acquire skills and developmental milestones
Developmental services coordinator (DSC)	person appointed to manage the referral process for all children about whom there are developmental concerns
Developmental surveillance	a shared parent/health professional activity which uses both parties' knowledge about the child to monitor development in an ongoing way
Developmentally appropriate practices	activities, materials, curriculum and environment consistent with the developmental stage of the child
Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV)[30]	diagnostic and statistical manual of mental disorders. Now superseded by Diagnostic and Statistical Manual of Mental Disorders – 5th Edition (DSM5)[29]
Differential diagnosis	alternative possible diagnosis. Also commonly used to mean the different diagnostic possibilities which need to be considered in a particular situation
Disability Information Advisory Service (DIAS)	Disability Information Advisory Service
Discrete trial training (DTT)	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.
Distance learning	instruction that is not face-to-face (i.e., is by mail or electronic means)
Dolman-Delacato method	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.
Dolphin therapy, or dolphin-assisted therapy	see Animal therapy
Dyskinesias	Impairments in the control of ordinary muscle movements. Can be caused by use of some medications especially antipsychotics.
Dyspraxia	difficulty in the planning and execution of purposeful movements that result in difficulty performing fine and gross motor skills (e.g., drawing, buttoning, dressing, learning new motor skills and speech, etc). Also known as developmental coordination disorder.

EarlyBird	a parent-education programme for parents of young autistic children originally developed in the United Kingdom
Early Intensive Behavioural Intervention	The Living Guideline Group provided this definition following their update on applied behaviour analysis.[15] 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.[204] The common elements of EIBI programmes, paraphrased from Eldevik et al,[443] are as follows: (a) intervention is individualised and comprehensive, addressing a range of skills (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 (c) one or more individuals with advanced training in applied behaviour analysis and experience with young children with developmental disabilities (especially autism) directs (supervises) the programme (d) the selection of intervention goals and short-term objectives is usually guided by understanding of developmental sequences (e) parents are encouraged to serve as active co-therapists for their children, and may be trained to do so

Early Intensive Behavioural Intervention (continued)	(f) intervention is delivered in one-to-one fashion initially, with gradual transitions to small-group and large-group formats when warranted (g) intervention typically begins in the home and is carried over into other environments (e.g., 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 (h) programming is intensive, is year round, and includes 20 or more hours of structured sessions per week plus additional informal instruction and practice (i) in those programmes that have been formally evaluated, the duration of intervention is usually 2 or more years (j) the intervention programme is usually commenced in the preschool years, when the children are 3 to 4 years of age.
Echolalia	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.
Eclectic approach	a teaching approach which draws on elements from many theoretical models
Eco-cultural	the ecology of the social and cultural influences surrounding the child and family/whānau
Ecological approach/ model	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.
Electroencephalogram (EEG)	a recording of the changes in electric potential associated with activity of the cerebral cortex. EEG is used in the evaluation of epilepsy.
Empathy	identification with and understanding of another's situation, feelings, and motives

Empirically validated strategies	strategies for which there is research evidence
Engagement	refers to the amount of time that a child is attending to and actively participating in the social and non-social environment
Enuresis	incontinence, the involuntary passing of urine. ‘Nocturnal enuresis’ refers to bedwetting.
Environmental barriers	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.
Environmental modification/adaption	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.
Epidemiology	the study of how a disease affects a population, i.e., incidence, control, distribution, etc
Epistaxis	nose-bleed
Ethnicity	refers to cultural factors, including nationality, regional culture, ancestry, and language. An example of ethnicity is German or Spanish ancestry (regardless of race) or Han Chinese. Your ethnicity is determined based on the social and cultural groups you belong to and is self-perceived. You can have more than one ethnicity. The terms ‘race’ and ‘ethnicity’ can be highly subjective, with lines between the two concepts frequently blurred.

Executive function	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.
Expressive communication	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.
Expressive language	sending information or messages to other people using verbal or non-verbal language
Extrapyramidal symptoms	neurological symptoms including tremors, muscle rigidity, a shuffling gait, restlessness, and difficulty initiating movement
Eye contact	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.
Evidence-based recommendations	recommendations that are supported by evidence from a systematic review of the literature.
Facilitated communication (FC)	technique used for people with communication difficulties whereby they are supported to point to or touch objects, letters, symbols, or pictures
False memory	memory of an event that did not happen or is a distortion of an event that did occur as determined by externally corroborated facts
Family-centred services	services, goals, and plans for a child that are based on family needs and preferences
Family Care Plan (FCP)	a support plan to meet the individual needs of children and their families, usually around early support services

Floor Time[255]	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
Formulation	the process of integrating assessment information systematically
Fragile X	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.
Functional alternative	a behaviour that serves the same function as current 'behaviours of concern'. Teaching functional alternative behaviours helps to eliminate the undesirable behaviour by reducing the need for it.
Functional analysis	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. 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.
Functional assessment	the observation phase of functional analysis. Sometimes referred to as 'functional behaviour assessment'.
Functional communication	how the child communicates in their everyday environments which may include a range of communication forms, e.g., signs, gestures, visual symbols or language
Functional communication training	is often part of a programme where a 'behaviour of concern' serves a communicative function. Acceptable functional alternatives to the 'behaviour of concern' are taught so that the child is able to communicate appropriately.
Functionality	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
Further education	tertiary education (university or polytechnic), adult education, and vocational training schemes

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.
Generalisation	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’.
General paediatrician	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 Aotearoa New Zealand are general paediatricians.
Gentle teaching	non-violent approach for helping people with disability and sometimes ‘behaviours of concern’
Gluten-casein free diet	a diet which contains no gluten (a protein found in many cereals such as wheat) and no casein (a protein found in milk)
Health care professionals (HCPs)	an umbrella term for all professionals working in the health care field. It includes doctors, nurses, physiotherapists etc.
Hidden curriculum	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)
Higashi Schools therapy	therapy which uses group dynamics, physical education, art, music, academic activity, and vocational training. Also known as Higashi.
High functioning autism (HFA)	those autistic people/tāngata whaitakiwātanga without any intellectual disability, 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 (no longer a diagnosis under DSM5)[29]
Holding therapy	forced holding by a therapist or parent until the child stops resisting or until a fixed period has elapsed

Hyperactivity	continual, inappropriate motor activity
Hyperarousal	a state of excessive arousal or wakefulness
Hyperlexia	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
Hyperprolactinaemia	excess secretion of the hormone prolactin
Hypersensitivities	acute, often painful physical sensation or reaction to sensory input due to over responsivity of sensory systems
International Classification of Diseases, version 10 (ICD-11)	International Classification of Diseases, version 11
Ideation	thinking
Incidence	rate of occurrence of new cases of a particular disease or condition in a population
Incidental teaching	systematic instruction which is delivered in the context of natural routines and play activities in everyday environments
Inclusion	refers to the philosophy, policy and practice of providing participation and learning opportunities for all children according to their needs
Inclusive settings	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
Individual Education Programme (IEP)	the individual planning process which is the basis of collaborative planning between home, school, and specialist services. Goals are based on the Aotearoa New Zealand curriculum.
Individual (Development) Plan (IP or IDP)	a plan which is sometimes used in early childhood education services. Goals are based on Te Whāriki, the early childhood education curriculum.
Individual profile	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.

Insight-oriented therapy	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
Intellectual disability	a condition manifested before the age of 18, in which people have both significantly subaverage intellectual functioning, and significant deficits in adaptive function
Intensity	‘dose’ of ‘treatment’ in a support programme
Irlen lenses	lenses prescribed and supplied by the Irlen Institute and others to alleviate symptoms of Scotopic Sensitivity Syndrome
Islets of ability	see savant skills
Joint attention	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.
Joint attention routines	technique used in applied behaviour analysis and some other approaches
Karyotype	the analysis of an individual’s complement of chromosomes
Kanner type	used to describe those individuals most similar to the group of children described by Leo Kanner in 1943. These individuals tend to have higher and complex support needs. Not a diagnosis under DSM-5[29]
Key worker	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 autistic individual or family and for other agencies who are also involved.
Lability	readily or frequently undergoing change (lability of mood refers to fast and frequent mood changes)
Language	a rule-based form of communication. Includes a set of conventional symbols (e.g., spoken words, signs, written words) that is shared by members of a community or culture
Learning Experiences: An Alternative Programme for Preschoolers and Parents (LEAP)[253]	approach in which very young autistic children are taught alongside non-autistic children

Learning Stories	form of narrative assessment (often used by early childhood teachers)
Least restrictive environment	is a mandate or requirement in the United States. It means that each child should be accommodated in the least restrictive setting (i.e., 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.
Lovaas Method	programme of applied behaviour analysis developed by Dr O. I. Lovaas.[204] Also known as Young Autism Project and Early Intensive Behavioural Intervention.
Magnetic resonance imaging (MRI)	a form of medical imaging which uses a strong electromagnet. It provides detailed pictures of the structure of the body or the brain.
Maintenance	evidence that the behaviour change has continued over a period of time
Masking	masking, 'social camouflaging', 'compensation' and 'pretending to be normal' is a phenomenon where an autistic person/tangata whaitakiwātanga monitors and modifies their behaviour, consciously or not, to conform to conventions of non-autistic social behaviour. It can be considered a coping strategy, and may be harmful to autistic people/tāngata whaitakiwātanga.[215]
Mentoring	the practice of assigning a person to a more experienced person to provide advice or guidance
Mind map	visual aid to show a logical sequence of ideas
MMR	a vaccine containing modified live viruses to protect against infection with the diseases measles, mumps and rubella (German measles).
Mnemonic device	aid such as a verse or acronym to aid one's memory
Model	the theoretical base or description of a programme or approach, e.g., behavioural or developmental model
Motivation	a stimulus to action; something (a need or desire) that causes one to act
Motor Skills	skilled performance of motor tasks (e.g., 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.

Multiagency	involving two or more agencies or personnel from two or more agencies
Multidisciplinary team	professionals who have a range of skills and develop their own goals and support plans
Music therapy	using music as a tool for communication or as non-verbal symbolic means of expression
Narrative assessment	using narrative as a way of assessing children's learning, for example, learning stories
Natural contexts	the settings, people and equipment that would be associated with everyday activities
Natural settings	the usual settings that would be associated with everyday activities. For example, teaching about shopping in a supermarket rather than a classroom.
Naturalistic teaching	using natural contexts to teach skills
Needs Assessment and Service Coordination (NASC)	Needs Assessment and Service Coordination
Negative Reinforcement	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.
Neuro-biological	the biology or science of the nervous system
Neurodiversity	A term to describe neurological differences in the human brain which recognises such natural variation as difference rather than deficit. The concept of neurodiversity has foundations in neuroscience, with studies of neuroimaging (brain imaging) showing differences between individuals' neural pathways – those who are neurotypical and those with neurodiversity. This term was coined in the late 1990s as a challenge to prevailing views of neurological diversity as inherently pathological, and it asserts that neurological differences should be recognised and respected as a social category on a par with gender, ethnicity, sexual orientation, or disability status.

Neurotoxicity	effects of a substance (e.g., a medication or chemical) which is toxic or damaging to the brain or nervous system or both
Neurotransmitter	the chemical messenger which plays a part in the transmission of messages from one neuron or nerve cell to another
Neurotypical (NT)	neurologically typical. A word to describe neurologically typical (and sometimes, non-autistic) individuals.
New Zealand Association of Occupational Therapists (NZAOT)	professional association of occupational therapists
New Zealand Health Technology Assessment (NZHTA)	New Zealand Health Technology Assessment, a clearing house for health outcomes and health technology assessment based at the University of Otago, New Zealand
NGO	non-governmental organisation
Non-verbal communication	non-symbolic form of communication; ie. body language, facial expressions, tone of voice, eye gaze to convey meaning rather than a symbol (word, picture, sign)
Obsessive-compulsive disorder (OCD)	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
Occupational therapist (OT)	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
Off-label	describes the prescription of a drug outside the manufacturer's recommendations for that drug
Ongoing Resourcing Schemes (ORS)	Ongoing Resourcing Schemes provide resources for a very small group of school students throughout Aotearoa New Zealand who have the highest need for learning support. Most of these students have this level of need throughout their school years.
Options method	see Son-Rise
Oranga Tamariki	Ministry for Children
Over-selectivity	the trend to respond only to part of a stimulus rather than the whole object or to the whole social setting
Pacific/Pacific peoples	the people, cultures, and language of Pacific groups including: Sāmoa, Tonga, the Cook Islands, Niue, Tokelau, Tuvalu, and other smaller Pacific nations – who are now living in Aotearoa New Zealand

Paradoxical responses to stimuli	unexpected reactions to sensory input
Paraprofessional	person who supplements or supports the work of a professional such as a teacher, e.g., teacher's aide, support worker
Parent-managed applied behaviour analysis	behavioural intervention developed and implemented by parent with limited training
Patterning	range of therapies which use a series of bodily exercises and other activities which are intended to 'rewire' the brain
Peer-mediated techniques	programmes/strategies using peers as co-therapists, or including peers as tutors or teachers
Peer tutoring	using the child's peers as tutors or teachers
Perceptual distortions	distortions of the visual senses, programme difficulties in looking at print
Perceptual organisation	assessment of the process of 'thinking', including perception, reasoning, problem solving and memory
Periodontitis	inflammation of the tissue surrounding the neck and root of a tooth
Perseveration	repetitive movement or speech, or sticking to an idea or task, that has a compulsive quality to it
Perseverative behaviour	engaging in Perseveration (*see above*)
Person-centred planning	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
Pervasive Developmental Disorder (PDD)	another term for autism spectrum disorder
Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)	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
Pet therapy	see animal therapy
Pharmacotherapy	the use of medications or drugs to treat disease
Pharmacodynamics	the science of the action of drugs
Pharmacokinetics	the study of the way a particular drug behaves in the body, e.g., how rapidly it is absorbed and how quickly it is broken down by the body

Phenotype	the visible characteristics or traits which characterise an individual or a group of individuals
Physiotherapy	assessment and treatment therapies conducted by a physiotherapist, e.g., exercise, adaptations to support physical participation in the curriculum
Picture Exchange Communication System (PECS)	an augmentative communication training package (developed by Andrew S Bondy and Lori Frost) that teaches autistic children and adults and those with other communication challenges to initiate communication. PECS developed from applied behaviour analysis.
Pivotal response training (PRT)	a technique targeting pivotal skills (motivation, self-management, and initiating interactions, for example) that are expected to be associated with wider behaviour change[206]
Pivotal skills	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.
Play dates	social opportunities with peers usually conducted within the home
Play-oriented strategies	the use of play to achieve learning goals
Play therapy	therapy in which play is used to help individuals to address and resolve their own problems
Plunket	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 Aotearoa New Zealand.
Positive behavioural approaches	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 'behaviours of concern'. Positive behavioural support typically involves changing existing environments in a manner that makes 'behaviours of concern' irrelevant, ineffective, and inefficient.

Positive reinforcement	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.
Power cards	cards which an individual carries to remind him or her how to deal with a difficult situation
Pragmatic (aspects of communication)	the practical aspects communicating in natural settings, for examples social rules about eye contact, taking turns, observing body language, selecting topics of conversation, etc.
Pre-linguistic communication	communication features such as joint attention, gesture, eye contact, vocalisations etc that form the basis of expression prior to spoken language development
Prevalence	percentage of a population that is affected with a particular disease or condition at a given time
Priapism	persistent and painful erection of the penis
Programme	a particular service with carefully planned steps, e.g., CARD or LEAP
Prompt-dependent	an individual can only perform an action following the prompt that was associated with the learning. The learning has not been generalised.
Prompt (verbal, physical)	a cue or hint (picture, words, touch) meant to induce a person to perform a desired behaviour
Proprioception	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
Prosody	the variation of tone in spoken language
Psychodynamic therapy	psychological therapy based on the teaching of Sigmund Freud and neo-Freudians
Psychological hardiness	resilience, the ability to 'survive' or maintain adaptive function despite major stressors or challenges
Psychometric	the measurement of mental and psychological ability, potential and performance, especially measurement of intelligence

Psychosocial	relating to both psychological and social factors
Psychotherapy	the treatment of mental disorders by psychological methods
Psychotropic	relating to a medication or drug that has an effect on the individual's psychological functioning or behaviour
Randomised controlled trial (RCT)	an experiment in which two or more interventions, possibly including a control intervention or no intervention, are compared by being randomly allocated to participants
Receptive communication	the understanding of that which is said, written or signed
Receptor antagonist	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.
Regional Intellectual Disability Care Agency (RIDCA)	Regional Intellectual Disability Care Agency
Regional Intellectual Disability Supported Accommodation Services (RIDSAS)	Regional Intellectual Disability Supported Accommodation Services
Reinforcement	any event, stimulus, or behaviour which, when made contingent on a response, serves to increase the frequency or likelihood of occurrence of that response
Reinforcer	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.
Relationship development intervention (RDI)[209]	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
Repetitive behaviour	repeating the same behaviour over and over, e.g., rocking for hours
Resource Teacher of Learning and Behaviour (RTLB)	itinerant consultant in the Aotearoa 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

Respite care	skilled adult supervision to give primary carers an opportunity for relief from the demands of caregiving
Rett syndrome	a syndrome, seen mainly in girls, who characteristically show typical 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 affected 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.
Role play	acting out of a role as a means of practising a response
Rote drill	repeated learning or drilling of facts (such as times tables)
Round (or length of round)	the quantity of information in one ‘turn’ of an interaction between individuals
Savant skills	An autistic individual who may have exceptional skills in a particular area
Scaffolding	supporting learning
Scotopic sensitivity syndrome	condition in which individuals are especially sensitive to lights, glare, patterns, colours, and contrast. See Irlen lenses
Scripts	using written narratives to teach appropriate skills, e.g., going to the library
Script fading	gradually using less information in the scripts until the skills can be used without the script
Segregated settings	environments in which children are separated from their non-autistic peers for reasons relating to their disability or diagnosis
Self-injury	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.
Selective serotonin re-uptake inhibitor (SSRI)	an antidepressant medication
Self-stimulatory behaviour	(also known as *stimming*), also known as self-stimulation – a term for behaviours whose purpose appears to stimulate one’s senses. Many autistic people/tāngata whaitakiwātanga report that some self-stimulation may serve a regulatory purpose (i.e., calming, increasing concentration, or shutting out overwhelming sensory input).

Semantic	relating to the meaning of language
Sensory impairment	challenges in sensory function (e.g., 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 well-being.
Sensory integration	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
Sensory modulation	ongoing physiological process central to the ability to filter or attend selectively to sensory information
Sensori-motor handling	a broad range of unrelated treatment techniques focusing on the sensory or motor systems, e.g., reflex integration, neuro-developmental therapies, patterning etc
Sensory overload or defensiveness	a group of traits 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.
Sensory stimulation	sounds, smells, tactile sensations, and other inputs which stimulate the senses
Serotonin	a neurotransmitter involved in, for example, sleep and depression and memory
Shared positive affect	positive or pleasurable shared experiences between children and others
Sialorrhoea	excessive production of saliva; drooling
Sibkids	online support group for siblings
Social communication	the skills that allow people to interact with and influence others and gain some control over the environment
Social Communication Emotional Regulation Transactional Supports (SCERTS™)[207]	multidisciplinary educational approach 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
Social decision-making strategies	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

Social model of disability	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
Social skill repertoire	the set of social skills (positive appropriate social behaviours) that an individual possesses
Social skills groups	approaches which provide structured sessions in social skills training in small groups of people of a similar age group and with similar social challenges. 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.
Social stories[231]	narratives written about social situations to assist understanding, to help the person manage their anxiety and sometimes to encourage appropriate behaviour
Social validity	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, i.e., that meets a practical or social need for this child and their family
Son-Rise[444]	intensive training programme based on the idea that the best way to help an autistic child is to follow the child's lead. Also known as the Options method.
Special Education Needs Coordinator (SENCO)	a person in some schools who coordinates programmes for children with learning support needs
Specialised curriculum	a curriculum which is tailored to meet the needs of the autistic child. Such a curriculum usually emphasises social and communication skills.
Speech	the act of speaking
Speech-language therapist (SLT)	therapist trained to work with individuals to help them develop their communication skills using a range of techniques
Splinter skills	see Savant skills
Spontaneous communication	unprompted communication

Stereotypies	persistent postural, gestural or verbal responses that are without apparent meaning and tend to recur inappropriately
Stimming	see Self-stimulatory behaviours
Structure	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.
Structured environments	environments which are planned to ensure that students have a clear comprehensible programme and environment
Supported employment	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 (e.g., 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. 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.
Symbolic or dramatic play	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
Symptom substitution	where an individual learns to eliminate one behaviour, but substitutes another behaviour to get the same gain
Systematic instruction	planned, explicit, intentional teaching based on thorough assessments
Tactile	relating to the sense of touch
Tactile defensiveness	hypersensitivity to senses of touch
Tardive	characterised by tardiness, lateness. Used for disorders in which characteristic symptoms appear relatively late in the normal course of the disorder.

Tardive dyskinesia	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.
Task analysis	analysing a task to identify the individual elements
Task organiser	breaking a task into small steps which are presented in written or visual form
TEACCH (Treatment and education of autistic and related communication-handicapped children)	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
Theory of mind (ToM)	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
Tic	a habitual stereotyped movement or complex of movements. The individual is aware of the movement but is unable to prevent the movement from happening.
Time-out (from reinforcement)	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.
Tourette syndrome	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.
Transition	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.
Trial teaching	using assessment to determine a child's rate of learning using particular strategies during a trial period
Tuberous sclerosis	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.

Typically developing peers	children whose development is following the expected path
Twilight time	(in relation to teachers) the time after school or in the evening
Verbal language	a system of conventional symbols (spoken and written words, signs or visual code) that have shared meaning for members of a community or culture who use a common language.[40] Not restricted to speech. Includes use of AAC.
Vestibular	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.
Video modelling	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.
Visual (cuing, supports, symbols)	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 autistic individuals to function more independently without constant verbal directions.
Visual therapy	therapy which aims to improve visual processing or visual spatial perception
Visual-spatial skills	cognitive abilities that relate to the way people perceive the objects and surroundings of their environment
Vocational services	employment services, or services which find or provide meaningful daytime activities
Well Child/Tamariki Ora	The Well Child/Tamariki Ora Framework covers screening, education and support services offered to all Aotearoa 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 (*see also Tamariki Ora in Glossary of Māori and Pacific Terms*).
Young Autism Project	see Lovaas method

Glossary of Māori and Pacific terms

Aroha	love in its broadest sense
Ahuatanga Māori	Māori tradition
Fono	to gather together; have a meeting
Haka	fierce rhythmical dance
Hui	a gathering following Māori protocols
Iwi	tribe, bone, people
Kai	food
Kaiarahi	guide
Kaiawhina	support person
Kanohi ki te kanohi	face-to-face communication
Kanorau ā-io	neurodiversity (kanorau =diversity, ā-io=of the nerves)
Kanorau ā-roro	neurodiversity (kanorau =diversity, ā-roro=of the brain)
Karakia	prayer, ritual chant
Karanga	ritual call of arrival and welcome
Kaumātua	respected elder (men and women)
Kaupapa	purpose
Kawa	protocol, procedure
Kōhanga reo	Māori-medium early childhood education centre
Kuia	respected female elder
Kura kaupapa Māori	Māori immersion school based on Māori culture, practices and philosophies
Mahi	work, job, employment, trade (work), practice, occupation, activity, exercise, operation, function
Manaaki	care for, provide support in a respectful manner
Mana atua	Well-being
Mana aotūroa	exploration
Mana reo	observing the local language of the region
Mana tangata	people upholding the prestige of the local area
Mana whenua	tribal people of the local area
Marae	cultural meeting ground or place
Mihi	greet, introduction

Pakeke	adult/s
Poi	swinging ball used in a traditional dance
Pono	truth, a validity principle
Pōwhiri	formal welcoming ceremony
Rangatahi	young person/people
Raranga	weaving
Rūnanga	regional Māori council
Takiwātanga	autism (in his/her/their own time and space)
Taiaha	long-handled, two-handed weapon used in traditional Māori martial art form
Tamaiti	child
Tamariki Ora	Well Child – a national schedule of services that provides screening, surveillance, education and support services to all Aotearoa New Zealand children from birth to five years and their family or whānau
Tamariki	children
Tangata whaitakiwātanga	autistic person (see takiwātanga)
Tāngata whaitakiwātanga	autistic people (see takiwātanga)
Taonga	treasure, anything prized
Tapu	sacred
Te reo Māori	the Māori language
Te Whāriki	the Aotearoa New Zealand early childhood curriculum
Te Whare Tapa Whā	framework of Māori health (four-sided house)
Tika	authentic, observing custom
Tikanga	customs, protocol, rules, principles
Tohunga	expert
Waiata	song
Wairuatanga	spirituality
Wairua	spiritual
Waka-ama	outrigger canoe paddling
Wānanga	discussion, place of learning. Also the name of a publicly owned tertiary institution that provides education in a Māori cultural context.
Whakamā	shy, embarrassed
Whānau	extended family
Whanaungatanga	kinship, relationship

Appendices

“Kua takoto te mānuka”

The mānuka (challenge) has been laid down

Appendix 1: Guideline development process

Methodology for the First Edition

The development of the Guideline's first edition was initially based on a phased approach where the work was discretely divided into 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 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 (now Learning Support) 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 autistic students
- professional learning and development for professionals working in education.

3. The Disability Services Directorate in the Ministry of Health (now in Whaikaha – Ministry of Disabled People) 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 onto the group, including an 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 autism. 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 autism 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 on the development of the 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 autism-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)[14], 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. 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,[61] 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[445] to assess the NAPC Guideline[14]. It was assessed as being an appropriate document to be adapted for the Aotearoa New Zealand environment. Some areas identified by the AGREE assessment required adaptation to reflect the Aotearoa New Zealand context. Adaptation of the NAPC Guideline[14] 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 approaches suitable for autistic children 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 autism
- double-blind randomised controlled trials
- systematic reviews
- case reports of adverse effects (with particular reference to drugs in current use in Aotearoa 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 autism and related conditions. 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 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 autistic adults. 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 Part 2 and all of Part 3 of the Guideline were developed by a small working group consisting of five people with expertise in learning support and autism. 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 of autism. The criteria for the 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 autism.

Recurring themes were identified. The published evidence was critically appraised and evidence tables were 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 autism subject matter experts from across Aotearoa 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 autistic people/tāngata whaitakiwātanga 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 on the autism spectrum were excluded:

- skills for independent living
- socialisation, relationships, and sexuality
- behaviour support
- occupational therapy
- physiotherapy
- communication support
- care and protection
- alternative approaches
- interface between relevant Aotearoa New Zealand agencies
- autistic people/tāngata whaitakiwātanga over the age of 65 years
- transitions within the education system, 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 regularly during the development of the sections.

The 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 updates of the Guideline conducted through the Living Guideline process, systematic searching commenced 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 Aotearoa New Zealand and overseas. A parallel review of the draft Guideline was also undertaken by several experts in autism nominated by the workstream leaders. Feedback was sought on the 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 the first edition of the Guideline can be requested from Whaikaha – Ministry of Disabled People. 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[14]. 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 the 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. Evidence Tables for the 14 topics updated through the Living Guideline process are presented in their relevant Supplementary Papers and available from Whaikaha – Ministry of Disabled People’s website.

Grading

Each of the recommendations in this Guideline is followed by a ‘strength of evidence ‘ grading, designated by the letters ‘A’, ‘B’, ‘C’, or ‘I’ 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. Before this decision was made, Workstream 1 had used the grades applied by the NAPC UK Guideline[14]. 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 was 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, e.g., 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 lived experience, cultural experience and/or professional expertise of members of the Guideline Development Team or Living Guideline Group, 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 Aotearoa 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 a programme/strategy works or A evidence that it doesn’t work (and that therefore the programme 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 programmes. Nevertheless, there may be a universal consensus among autism researchers that such a 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: Guideline writing teams and management groups

2.1 Writing teams

The members of the first edition's 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

Giles Bates
Paediatrician

Tanya Breen
(co-leader of Workstream 3)
Consultant Clinical Psychologist

Veronica Casey
Former CEO, Paediatric Society of New Zealand

Matt Eggleston
Child and Adolescent Psychiatrist

Monique Faleafa
(expert in Pacific Peoples' issues)
Clinical psychologist/Pacific advisor

Jill Ford
Service Manager and occupational therapist

Andrea Hasselbusch
Occupational therapist

Lynne Hayes
Speech-language therapist

Anne Lethaby
Technical Editor (1st edition), independent evidence-based consultant

Dannette Marie
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Department of Psychology, University of Otago, Dunedin

Rosemary Marks
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Developmental Paediatrician

Andrew Marshall
Developmental Paediatrician

Keryn Mells
Primary teacher and a 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

Sue Robertson
(coleader of Workstream 3)
Parent for an autistic person

Adrienne Tomkins
Speech-language therapist

Marilyn Watson
(leader of Workstream 2)
Registered psychologist

The following individuals and groups made additional contributions and are thanked for their support and advice in developing this Guideline:

Christina Birkin; Rowena Cave, Carolyn Doughty, Catherine Marshall, Isobel Martin, Anna Pethig, Hilary Rendell, Mereti Taipana, John Werry, Tu Williams.

2.2 Consultation advisory groups

Advisory group for Workstream 1

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Senior Occupational Therapist

John Clarkson
Paediatrician

Tony Hanne
General Practitioner

Brenda Hynes
National Clinical Advisor (Nursing)

Fran Moore
Nurse

Ulla Preston
Psychologist

Stephen Voss
General Practitioner

Advisory group for Workstream 2

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Massey University

Jen Birch
Autistic person

Marg Crosswell
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Marilyn Glover

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Lynne Hayes
Speech-language therapist

Mary Henderson
Parent/representing families of autistic children/young persons

Chris McGuire
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John McKeown
Principal

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Cheryl Palmer
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Maryanne Pease
Psychologist/Service Manager

Grant Ramsay
Early intervention teacher

Mary Smith
Verifier

Clair Wilson
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Ans Wilkin
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Maree Whitworth
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Advisory group for Workstream 3

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Jen Birch
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Stephanie Charteris
Occupational therapist

Mary Foster
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Nan and Soren Jensen
Parents of an autistic person

LeAnne Kingi
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Dave Lennard
Autistic person

Steven Lillas
General practitioner

Chris McGuire
Parent/Autism New Zealand

Amica Petrova
Psychiatrist, Child and Adolescent Mental Health

Angela Preston
NASC representative

Alison Schroeder
Speech-language therapist

Raewyn and Martin Upsdell
GP and scientist (respectively) and parents of an autistic person

Robyn Ward
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Jan White
Disability Support Link

Maree Whitworth
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Anne Wilkinson
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Advisory group for Māori perspectives

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Leo Buchanan
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2.3 Steering Group

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Dave Lennard
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2.4 Senior Officials Group/ASIWG

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2.5 Living Guideline Group membership

Jill Bevan-Brown (past LGG Member)
Director (retired), Institute of Education, Massey University

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Donna Caddie (LGG ex-officio)
Ministry of Education

Joanna Curzon (past LGG ex-officio)
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Elizabeth Doell (LGG member, past LGG ex-officio)
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Matt Eggleston (LGG Chair)
Child and Adolescent Psychiatrist

Ian Evans (past LGG Chair)
Emeritus Professor of Psychology, Massey University

Debbie Fewtrell (past LGG Member)
General Practitioner (professional interest in autism spectrum disorder)

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Natasha Gartner (past LGG ex-officio)
Ministry of Health

Helen Hayes (LGG ex-officio)
Whaikaha – Ministry of Disabled People

Pamela Henry (past LGG ex-officio)
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Julie Hook (past LGG ex-officio)
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Sue Kinnear (past LGG member)
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Andrew Marshall (LGG Deputy Chair)
Developmental Paediatrician, and Clinical Leader, Child Health, Wellington Hospital

Martyn Matthews (LGG member)
Research consultant, Kestrel Consulting

Victoria Parsons (past LGG ex-officio)
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Gordon Sinclair (past LGG ex-officio)
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Daniel Smith (LGG member)
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Leigh Sturgiss (past LGG ex-officio)
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Dorothy Taare-Smith (LGG member)
Taonga Takiwātanga Charitable Trust

Larah van der Meer (LGG member)
Autism researcher, Autism New Zealand

Appendix 3: Summaries of Living Guideline Supplementary Papers

3.1 Summary of Supplementary Paper on applied behaviour analysis

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 supports and strategies based on applied behaviour analysis (ABA) in relation to outcomes for autistic people/tāngata whaitakiwātanga. 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),[446] and

(ii) a consortium of Aotearoa New Zealand academics with expertise in ABA, led by Dr Oliver Mudford at the University of Auckland.[447]

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.

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 are available from Whaikaha – Ministry of Disabled People's website.[15] Supporting evidence reviews can be downloaded from other online sources.[446-448]

Living Guideline Group process

A Living Guideline process was set up to keep the 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 in December 2007, a review update of additional high-level secondary evidence (systematic reviews) published in August 2009 was undertaken.[448] 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

For the third edition of the Guideline, an additional commentary was prepared in a section titled "Concerns around ABA: Updated commentary for the third edition". It should be considered alongside the original Supplementary Paper on this topic.

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 supports based on the principles of applied behaviour analysis: *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), and the United Nations Convention on the Rights of the Child (1989).

Review of ABA evidence and impact on recommendations

Unchanged recommendations	Grade
3.2.5.2 Educational supports should incorporate principles of positive behaviour support, particularly a focus on understanding the function of the child's behaviour. **Additional text:** The use of the term positive behaviour support in the Guideline has caused confusion due to the implication that it might refer to a different, specific support package called 'Positive Behaviour Support.' For an understanding of positive behaviour support as a general set of professional standards and values, see discussion under Part 3, section 3.2.e under "positive behaviour supports" of the Guideline. **Rationale:** 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.	A

Revised recommendations	Grade
4.3.4 Behaviour management techniques should be used to intervene with problem behaviours. *Changed to:* **4.3.4** Behaviour management techniques should be used to intervene with 'behaviours of concern' following functional behaviour assessment. **Rationale:** 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 Guideline (Part 4, 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 an approach to respond to 'behaviour of concern' 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. An additional revision for the third edition was to replace 'problem behaviour' with 'behaviour of concern'. The term 'challenging behaviour' is also commonly used. The use of 'problem behaviour' can be perceived as implying the autistic individual is deliberately doing something wrong or 'being naughty' or 'difficult'. However, the behaviour is the problem, not the person, and the challenge lies in how to support them. The behaviour may be a concern to themselves (such as self-harm) or it may only be a concern to others who do not understand its purpose (e.g., shutdown from sensory overload). Addressing this concern therefore does not necessarily imply the need to eliminate or replace the behaviour. In specific situations, where possible, the behaviour should instead be described with respect to the autistic person's experience (e.g., sensory overload, stimming, expression of distress).	A
4.3.6 Consumers of behavioural interventions should refer to recently published guidelines for identifying, selecting and evaluating behaviour analysts with autistic people. *Changed to:* **4.3.6** Consumers of applied behaviour analysis supports should refer to the most recent published guidelines for identifying, selecting, and evaluating behaviour analyst services for autistic people. **Rationale:** Changed behavioural to applied behaviour analysis to be more explicit about the recommendation being linked with considered evidence. Note that the guidelines referred to have been updated.[308] The LGG decided no further supporting text is needed as the Guideline provides a rationale and outlines qualifications and training issues relevant to ABA. Also decided to reword for clarity with the addition of 'services for'. As this practice guideline is intended for funders and managers and not consumers, a new Good Practice Point 4.3.13 was developed by the LGG to guide autistic individuals and their families and whānau in decisions around supports and therapists.	C

New recommendations	Grade
4.3.5a Supports and strategies based on the principles of applied behaviour analysis should be considered for autistic children **Additional text:** applied behaviour analysis (or ABA) does not refer to one programme or technique. In the evidence considered by the LGG, there was little or no New Zealand-based research showing the appropriateness of ABA to the Aotearoa New Zealand context and population. 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. **Rationale:** The LGG decided to use 'based on the principles of applied behaviour analysis' to make connection with research evidence around applied behaviour analysis explicit as many approaches include behavioural components. The acronym ABA was removed as this can be understood to refer to a specific therapy. Agreed that the phrase 'supports and strategies' encompasses a range of approaches, as explained in the definition of applied behaviour analysis offered in the Glossary. Note that in the second edition, this recommendation referred to 'all children'. The word 'all' is removed for the third edition to ensure consistency with other Guideline recommendations and reflects evidence that such practices are not suitable for all children.	A

New recommendations	Grade
4.3.5b Early intensive behavioural intervention (EIBI) should be considered as an approach of value for young autistic children to improve outcomes such as cognitive ability, language skills, and adaptive behaviour. **Additional text:** 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 outcomes. We still cannot specify which attributes of participants, families, methods etc., are critical to outcome, apart from findings that higher IQ and language competence in individuals prior to receiving the programme are predictive to some extent of greater gains post programme, and at longer follow up. There is as yet insufficient research comparing high quality intensive 'other' approaches with EIBI to allow comparative judgements of relative effectiveness. There is a lack of knowledge about the suitability of EIBI for the diverse ethnic and cultural groups of Aotearoa New Zealand and for people with a diagnosis of Asperger Syndrome. 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 support effectiveness is therefore crucial (*refer to Recommendations 3.1.5 and 4.3.3*). **Rationale:** Uncertainty about the optimal intensity of hours, and who it benefits, is reflected in the grade allocated to this recommendation. As evidence relating to spontaneous, social communication competencies is equivocal, the recommendation refers to language skills.	B

New good practice points	Grade
4.3.11 Supports and strategies based on the principles of applied behaviour analysis should be relevant to the child's context and culture **Rationale:** The need to weave cultural sensitivity throughout the Guideline was agreed upon as important at the first LGG meeting.	✓
4.3.12 Supports based on the principles of applied behaviour analysis can be introduced before the diagnosis of autism is confirmed in a child displaying some of the characteristics of autism/takiwātanga **Rationale:** There was a concern about issues relating to diagnosis as some people have a delay in diagnosis which could delay effective support. Recommendation 3.1.1 supports this good practice point: '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)	✓

3.2 Summary of Supplementary Paper on pharmacotherapies

Preamble

Autism/takiwātanga can be associated with substantial challenges and autistic people and/or their caregivers can be particularly vulnerable to trying pharmacological approaches 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 approaches for autistic people/tāngata whaitakiwātanga: the atypical antipsychotic aripiprazole, the selective serotonin reuptake inhibitor (SSRI) citalopram, and the hormone, melatonin.

A systematic review was conducted updating evidence from the Guideline on these three pharmacological agents. Any controlled study assessing effectiveness was eligible for inclusion, as well as systematic reviews of these agents. Assessment of the updated evidence relevant to the three pharmacological agents resulted in several revised and new recommendations.

The full Supplementary Paper, describing the systematic review, the Living Guideline Group's (LGG) modified recommendations from the first edition of the Guideline, and newly developed recommendations and good practice points, is available from Whaikaha – Ministry of Disabled People's website.[16]

Aripiprazole

There was no mention of aripiprazole in the Guideline's 1st edition. 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 concerning 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 present. 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 are necessary before this medication is considered a first-line treatment in autistic people/tāngata whaitakiwātanga.

Revised recommendations	Grade
4.4.4 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
Changed to:	
4.4.4 In most circumstances risperidone should be the first medication used when indicated for significant irritability in children and young people on the autism spectrum. 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 Aotearoa New Zealand for autistic people/tāngata whaitakiwātanga.

The review identified preliminary open-label trials of the use of citalopram, for autistic people, two good quality systematic reviews, and a high-quality multi-centre, the triple-blinded study of 149 children and adolescents.

The LGG recognise that repetitive behaviours are not always a concern for an autistic person/tangata whaitakiwātanga 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 support.

The LGG discussed whether there may be a class effect generally with SSRIs, given the conclusions of a Cochrane review.[449] 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 on the autism spectrum. Caution was also urged in its use for established co-occurring 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 on adult populations. Caution is necessary for 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
4.4.1a Citalopram cannot currently be recommended for the treatment of repetitive behaviours in children and young people on the autism spectrum.	B
4.4.1b Citalopram's use for established co-occurring indications for children and young people (e.g., 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 identified and appraised four systematic reviews and one cross-over trial of good quality.

The LGG agreed that Recommendation 4.4.7 should be strengthened given the updated evidence. It is important to consider the level of impact on 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 autistic children, as many children on the spectrum 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 noted that the evidence has several 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[450] 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 schedule, and the avoidance of stimulants and late-night recreations.

Revised recommendations	Grade
4.4.7 Melatonin may be useful for improving sleep in autistic children who have impaired sleep. *Changed to:* **4.4.7** Melatonin can be recommended for use in children and young people on the autism spectrum who are experiencing significant sleep problems.	B

New recommendations	Grade
4.4.7a Benefits and adverse effects of longer term treatment of melatonin require further investigation.	C
4.4.7b Behavioural strategies (e.g., sleep hygiene) should always be used in conjunction with melatonin.	C

3.3 Summary of Supplementary Paper on supported employment

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 (e.g., 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 segregated, specially tailored settings and are commonly paid below-market-rate wages.

Autistic people/tāngata whaitakiwātanga 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 (i.e., 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 autistic young people and adults (aged 16 years or over)[17] which updated evidence from the 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.

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 Whaikaha – Ministry of Disabled People's website.[17]

Revised recommendations	Grade
5.1.9 Known support needs of autistic people who also have an intellectual disability should be taken into account when transitioning into any work environment. *Changed to:* **5.1.9** Any known support needs of autistic people, including those relating to cognitive ability, should be taken into account when transitioning into any work environment. **Rationale:** The updated evidence indicated that all autistic people 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 autistic people 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 autistic people may not have support needs requiring assistance from a supported employment service. Cognitive ability was considered by the group to be the more relevant and specific term.	B
5.1.10 Specialist employment services for autistic people should be developed. *Changed to:* **5.1.10** Supported employment services for autistic people should be developed, promoted, and expanded. Rationale: the term 'supported employment services' is used to refer to the services described as specialist employment services in the Guideline.	C
5.1.11 Specialist Employment Services should incorporate both known features of best practice employment for people with an intellectual disability and autism-specific strategies. *Changed to:* **5.1.11** Supported employment services should incorporate known features of best practice employment for people with an intellectual disability and autism-specific strategies. **Rationale:** Minor changes were made for improved readability and consistency with other recommendations and terminology.	B

Revised recommendations	Grade
5.1.12 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.	C
Changed to: **5.1.12** Any autistic characteristics 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. **Rationale**: Changed 'symptoms' to 'any autistic characteristics' in line with the positive framework the Guideline takes for autistic people and the recognition that characteristics 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.	B
5.1.13 Specialist employment services should work with workplace supervisors to maximise success in work placements. *Changed to:* **5.1.13** Supported employment services should work with employers, managers, and colleagues to maximise success in work placements. **Rationale:** Changes were made to ensure consistent terminology. The wording was changed to refer to workplace personnel more broadly and not just supervisors.	B

Note: Recommendation 5.1.8 was considered out of the 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
5.1.13a Supported employment services are recommended and should be available for all autistic people. **Rationale**: By recommending supported employment for all autistic people, 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 autistic people continue to experience inequity in employment.	B

New recommendations and Good Practice Points	Grade
5.1.13b Supported employment services should make available, where required: • Individualised job matching based on the person's career goals, strengths, and interests • Pre-placement assessment of work tasks and work environment • 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. • On-the-job provisions, including training on work tasks, acclimatisation to the work environment, social integration, developing of communication and interpersonal skills, and management of stress, and any contextually inappropriate behaviour • Job coaches with the level of support are determined by the need • Workplace modifications Long-term support in developing natural supports (e.g., upskilling managers) and, where needed, external supports (e.g., follow-up, assisting with issues that impact work). **Rationale**: 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 autistic client. Recommendation 5.1.13b emphasises that the workplace and staff need to consider how they may need to adjust to support the needs of an autistic worker 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.	B
5.1.13c Methodologically rigorous research is greatly needed to examine and improve the effectiveness of Aotearoa New Zealand-based supported employment services for autistic people. **Rationale**: As part of the systematic review update a wide search of grey literature in Aotearoa New Zealand was conducted. Whilst many supported employment services were identified, no evaluations were found which met inclusion criteria.	✓
5.1.13d Aotearoa New Zealand based research should consider the effectiveness of supported employment services for autistic people of different ethnicities. **Rationale**: 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.[61] Ethnicity is likely to be an important factor in the success of supported employment services in Aotearoa New Zealand also and worthy of future research reflecting the diversity of the local population.	✓

3.4 Summary of Supplementary Paper on gastrointestinal issues

Preamble

Gastrointestinal (GI) problems may be more common in autistic people/tāngata whaitakiwātanga than in the general population. The reasons why some conditions may occur more commonly in autistic people are not well understood.[14] Whilst GI problems arising in autistic people may have the same causes as GI problems in non-autistic people, some researchers have suggested that autistic people/tāngata whaitakiwātanga 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 does not have a 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, and 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 autistic children and young people (aged 18 years or under)[18] which updated evidence from the first edition of the 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.

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 Whaikaha – Ministry of Disabled People's website.[18] This document needs to be read in the context of the recommendations in the Guideline that all autistic children undergo a comprehensive health and developmental assessment.

Revised recommendations	Grade
4.6.1 When challenging behaviours are evident, autistic people need to be assessed for co-occurring conditions such as seizures, ADHD, anxiety disorders and depression. *Changed to:* **4.6.1** When 'behaviours of concern' are evident, autistic people need to be assessed for co-occurring conditions such as seizures, ADHD, anxiety disorders, depression, and gastrointestinal problems. **Rationale:** 'behaviour of concern' may be the primary or sole symptom of gastrointestinal problems. This evidence is based on consensus expert opinion and cross-sectional studies.	C

Note: Recommendations 2.3.9 and 4.1.4 remain unchanged.

New recommendations	Grade
4.1.4a and **2.3.9d** Gastrointestinal problems, specifically constipation, chronic diarrhoea, altered bowel habits, and encopresis (faecal soiling), are more common in children and young people on the autism spectrum compared with non-autistic peers. **Rationale**: There was a consistent trend observed across studies indicating that gastrointestinal problems were significantly more prevalent in children and young people on the autism spectrum than in non-autistic people. However, a grade of B was given to reflect the limitations of the evidence. Limitations to study designs introduce biases in determining the prevalence of GI outcomes in autistic individuals and non-autistic individuals, and lead to the wide variations evident in the current review. Major sources of variation between studies that impacted prevalence estimates include: • how the diagnosis of ASD in sample participants was made and confirmed • how the sample and control group members were identified and recruited • how gastrointestinal problems were defined • how gastrointestinal problems were assessed.	B
4.1.4b and **2.3.9e** Children and young people on the autism spectrum 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. **Rationale**: 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 on the autism spectrum can be more challenging due to the communication difficulties characteristic of autism/takiwātanga.	C

3.5 Summary of Supplementary paper on the implications of the DSM-5 for the Guideline

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[29] (DSM-5) 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 first edition of the Guideline needed to change to reflect them.

The Living Guideline Group process

The Living Guideline Group considered a review of evidence[19] relating to changes in the diagnostic criteria for ASD published in the DSM-5,[29] and the implications 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 Whaikaha – Ministry of Disabled People's website.[19]

Key changes in DSM-5

Key changes in the diagnostic classification of ASD in the DSM-5[29] 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[29]) 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. (1) social communication and social interaction
  2. (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 in the social-communication domain must be present and 2 of the 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 (e.g., 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[30] 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 the need for supports, including their intellectual ability, language challenges, and co-occurring medical conditions. Language delays 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 co-occurring conditions 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[29] 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 echoed the UK's National Autistic Society (NAS) in finding the DSM-5[29] revised diagnostic criteria helpful, being clearer and simpler than the previous DSM-IV[30] 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 observed that whilst Asperger syndrome may no longer be a distinct diagnostic entity diagnosed under the DSM-5[29], the concept retains clinical utility in terms of family understanding, self-identity, and as a tool for guiding educational and behavioural supports and informing services and supports.

The Living Guideline Group recognised 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 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 frequently throughout the text and recommendations the umbrella term of Autism Spectrum Disorder was used. Nevertheless, when the original Guideline was written the DSM-IV[30] manual was current and the terms Asperger syndrome and PDD-NOS were used in research. The Living Guideline Group advised that given the DSM-5[29], where these terms are used in the Guideline they should be read as referring to ASD or autism.

For the Guideline's third edition, the term autism is used where possible except when referring to research or diagnosis processes that require reference to specific diagnostic terms.

Revision of Guideline recommendations

Good Practice Points	Grade
1.3.5 Diagnosis of ASD in itself may be sufficient. Attempts to delineate ASD from Asperger syndrome may not be valid and are not necessary. *Deleted.* **Rationale:** 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.	✓

Revised recommendations	Grade
1.2.6 Test users should ensure that they are aware of the validity, reliability and appropriateness of tests when assessing autistic people and take these limitations into account when forming opinions and reporting results. *Unchanged.* **Rationale:** Some diagnostic tools in use are based on DSM-IV[30] criteria, however tools have been developed based on DSM-5[29]. It remains the case that the reliability, validity and appropriateness of assessment tools need to be considered when assessing for ASD.	C
1.2.5 Standardised autism, Asperger syndrome and ASD assessment interviews and schedules should be used. *Changed to:* **1.2.5** Standardised ASD assessment interviews and schedules should be used. **Rationale**: Words "autism, Asperger syndrome and" removed. Under DSM-5[29], DSM-IV[30] specified subtypes including autism and Asperger syndrome are subsumed under the one condition of ASD.	B B

Revised recommendations	Grade
1.2.7 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.	B
Changed to:	
1.2.7 The intellectual, adaptive and cognitive skills associated with ASD should be seriously considered and, where possible and appropriate, formally assessed.	B
Rationale: The words "assessment of" were removed as redundant in the sentence structure. Words "autism, Asperger syndrome and" removed. Under DSM-5[29], DSM-IV[21] specified subtypes including autism and Asperger syndrome are subsumed under the one condition of ASD.	
6.2 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
Changed to:	
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 Aotearoa New Zealand norms have not yet been established.	C
Rationale: 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[29], DSM-IV[21] specified subtypes including autism and Asperger syndrome are subsumed under the one condition of autism spectrum disorder.	
6.3 Norms should be developed for autism, Asperger syndrome and ASD assessment tools specifically for the New Zealand population.	C
Changed to:	
6.3 Norms should be developed for ASD assessment tools specifically for the Aotearoa New Zealand population.	
Rationale: Words "autism, Asperger syndrome and" removed. Under DSM-5[29], DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of ASD.	

New Good Practice Points	Grade
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. **Rationale:** 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.[30]	✓
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. **Additional text:** In addition, the LGG wanted it recognised that assessment decisions should consider whether a person wants or sees the need for a clinical diagnosis.	✓

3.6 Summary of Supplementary Paper on social skills groups for young people and adults

Preamble

Social skills groups refer to supports that provide structured sessions in social skills training in small groups of people of a similar age group and with similar social challenges. A session typically includes teaching a specific skill, demonstration of the skill through role-playing, the practice of the skill, and individualised feedback. Groups meet regularly, 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 supports. In particular, the LGG is aware that a 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) concerning the source of instruction. Peer-mediated approaches are based on interactions with trained, non-autistic 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 autistic children and young people (6–21 years)[20] which updated evidence from the 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 that focus on developing social skills for young autistic people/ tāngata whaitakiwātanga. Comparison groups were waitlist controls, or those receiving usual care. Eligible outcomes included social competence, social communication, emotion recognition, quality of social interaction/ play, ‘behaviour of concern’, 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 on the autism spectrum randomised to receive a social skills group programme with those randomised to waitlist control, usual care or no programme. The appraised body of evidence consisted of 12 studies, including two systematic reviews, and 10 RCTs.

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 Whaikaha – Ministry of Disabled People’s website.[20]

Revised recommendations

Revised 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. *Unchanged.* **Rationale:** This Recommendation was unchanged. It is broader in scope than the current research which focused on structured and facilitated social skills groups.	C

New recommendations and Good Practice Points

New recommendations and Good Practice Points	Grade
4.2.1a Facilitated and structured social skills groups should be considered for children and young people on the autism spectrum with less obvious support needs. **Additional text**: Social skills groups as referred to in this new recommendation are defined as programmes that provide structured sessions in social skills training in small groups of people of a similar age group and with similar social challenges. A session typically includes teaching a specific skill, demonstration of the skill through role-playing, the practice of the skill, and individualised feedback. Groups meet regularly, typically for 1–2 hours, for several weeks, facilitated by at least one trained instructor/therapist. Parents are typically provided training in concurrent sessions. Whilst it is acknowledged that the term 'high functioning' is not favoured in the context of autism/takiwātanga, 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[30] criteria). These individuals tend to have a means of communication but need support to develop appropriate pragmatic language skills. 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. 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 programmes conducted and evaluated in naturalistic settings, and into the generalisation and maintenance of acquired social competence and other salient outcomes. There is insufficient evidence relating to the relative benefits of social skills groups versus other group-based programmes, or individual social skills supports.	B

New recommendations and Good Practice Points	Grade
Rationale: 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 Aotearoa New Zealand context. 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).	
4.2.1b Social skills group approaches in Aotearoa New Zealand need to be responsive to the cultural and linguistic diversity of the group participants. **Rationale**: Further research is needed to explore the applicability and effectiveness of social skills groups in the Aotearoa New Zealand context.	✓
4.2.1c Decisions about participating in social skills groups should be guided by whether an autistic person values it, and whether they are expected to benefit from it. **Rationale**: Interest in participating in a social skills group was a common inclusion criterion 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 autistic person, their family, and the programme instructors, in deciding whether a social skills group is suitable. 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 Part 3, Section 3.2 of the Guideline, after Recommendation 3.2.2.4.	✓

3.7 Summary of Supplementary Paper on cognitive behaviour therapy for adults

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 that 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, and emotional and mental health outcomes of adults (aged 18 years and over) on the autism spectrum[18] which updated evidence from the Guideline on this topic. The review also aimed to describe recommended adaptions 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.

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 Whaikaha – Ministry of Disabled People's website.[21]

Revised recommendations

Revised recommendations	Grade
4.3.9 Cognitive behaviour therapy and related approaches should be considered suitable supports for many behavioural, emotion regulation and mental health challenges. *Unchanged.* **Rationale:** Recommendation 4.3.9 related to evidence for autistic people 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.	C
4.3.10 Cognitive behaviour therapists should adapt their techniques to take into account the characteristics of autistic people. *Unchanged.*	C

New recommendations and Good Practice Points

New recommendations and Good Practice Points	Grade
4.3.9a Broadly defined cognitive behaviour therapy, adapted for autism/takiwātanga, may assist adults with mental health conditions. **Additional text**: 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. It should be noted that the evidence base considered in developing this recommendation related to autistic adults who do not have an intellectual disability. **Rationale**: 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 autism/ takiwātanga. It was challenging to grade this new recommendation given the inconsistency of response of CBT, and the methodological limitations of the research.	C

New recommendations and Good Practice Points	Grade
4.3.9b Cognitive behaviour therapy (CBT) has been designed and evaluated predominantly for non-autistic people. 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 therapy effectiveness. **Additional text:** 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 therapy effectiveness with respect to these factors.	✓

New recommendations and Good Practice Points	Grade
4.3.10a The following adaptations to cognitive behaviour therapy are recommended: • **Use a structured approach** and minimise anxiety about the therapeutic process by being **explicit** about roles, times, goals, and techniques. • Extend the **number of sessions** and **time provided** to conduct tasks to accommodate slower information-processing and the mental demands of the therapeutic process. Be **flexible** about the length of each session and offer breaks to allow for cognitive and motivational challenges. • Provide **psycho-education** about autism/takiwātanga, emotion-regulation, and mental health challenges relevant to the client. • Concentrate on **well-defined** and **specific difficulties** as the starting point for supports, with less emphasis on changing client's cognitions. • Be more **active** and **directive** 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. • Teach **explicit rules** and their appropriate context, including the use of verbal, non-verbal, and paralinguistic cues to a social situation. • Incorporate specific **behavioural techniques** where appropriate, such as relaxation strategies, meditation, mindfulness, thought stopping or systematic desensitisation. • **Communicate visually** (e.g., using worksheets, images, diagrams, 'tool boxes', comic strip conversations, video-taped vignettes, peer-modelling, and working together on a computer). • **Avoid ambiguity** through minimising the use of colloquialisms, abstract concepts, and metaphors. Use specific and concrete analogies relatable to the client's concerns. • Incorporate **participants' interests** in terms of content and modes of content delivery to enhance engagement. • Involve a **support person**, such as a family member, partner, carer or key worker (if the autistic person agrees) as a co-therapist to improve generalisation of skills learned within sessions.	✓

3.8 Summary of Supplementary Paper on the impact of ethnicity on recognition, diagnosis, education, mental health, and other support for people on the autism spectrum

Preamble

The review related to ethnicity, which is defined by Statistics New Zealand[451] as the ethnic group or groups a person identifies with or has a sense of belonging to. It is a measure of cultural affiliation (in contrast to race, ancestry, nationality, or citizenship). An ethnic group is made up of people who have some or all of the following: a shared culture, such as traditions, customs, beliefs, or language; a common ancestry or history; a similar geographic, tribal, or clan origin. Ethnicity is self-perceived and a person can belong to more than one ethnic group. Ethnic minority groups are those that are numerically a minority in the broader population.

Living Group process

The Living Guideline Group considered a systematic review of evidence relating to the impact of ethnicity on the recognition, diagnosis, education, mental health, and other support services for people on the autism spectrum, and their family and whānau, which updated evidence from the Guideline on this topic.

Studies were reviewed where they compared the access, utilisation, or quality of services in these domains between service recipients from ethnic minority groups with those from non-minority groups. Studies that compared minority groups with the dominant population in countries most applicable to Aotearoa New Zealand were the focus, including New Zealand, Australia, the USA, Canada, and the UK. Studies of migrants or children of migrants in those countries were also of interest.

The appraised body of evidence consisted of 33 studies, including four systematic reviews and 29 primary studies (28 were cross-sectional, and one was a prospective cohort study). The review suggests that researchers evaluating the impact of ethnicity on services across the lifespan for people on the autism spectrum and their families/caregivers have tended to give the most attention to the identification, assessment, and diagnosis of ASD.

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 Whaikaha – Ministry of Disabled People's website.[22]

Revised recommendations and Good Practice Points

Revised recommendations and Good Practice Points	Grade
1.1.4: Age of detection/diagnosis of all developmental problems, including ASD as a specified disorder, should be audited. *Changed to:* **1.1.4:** Age of detection/diagnosis of all developmental problems, including ASD as a specified condition, should be collected and audited. This data should include ethnicity. Where disproportionate ethnic representation exists, reasons for disparities should be investigated and addressed. **Additional text**: Auditing This would help towards fulfilment of our obligations around data collection under the UNCRPD.[31] Refer also to Good Practice Points 7.5 and 8.7 regarding research data for Māori and Pacific peoples.	C C
1.2.13: The assessment psychometric properties of formal ASD assessment tools within the Aotearoa 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.	✓
1.2.6: Test users should ensure that they are aware of the validity, reliability and appropriateness of tests when assessing people for ASD and take these limitations into account when forming opinions and reporting results. *Unchanged.*	✓
1.4.6: Information on ASD and support services should be available at all diagnostic disclosure interviews and through health and disability services. *Changed to:* **1.4.6:** Information on autism/takiwātanga and support services should be available in a range of languages 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 autistic person. *Changed to:* **1.4.7:** Sources of post-diagnosis support should be identified for the person on the autism spectrum and be culturally responsive.	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. *Changed to:* **3.1.11:** A child's educational programme should reflect their interests and culture, and the developmentally appropriate learning models for their age. **Rationale**: The LGG identified significant relevant non-autism specific policy and research around this issue, for example, the Ka Hikitea and The Pasifika Education Plan.	C

Revised recommendations and Good Practice Points	Grade
3.2.5.1: Interventions should start early, as soon as problem behaviours are observed, 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. *Changed to:* **3.2.5.1:** Supports should start early, as soon as 'behaviours of concern' are observed, and be proactive. The child or young person's programme should be culturally responsive, individualised, and designed to engage the child or young person and provide a highly supportive environment.	B
3.4.3: When making a choice about educational placement, teams should consider whether the following factors are provided or can be created: • structure • opportunities for contact with typically developing peers • trained and stable staff • staff with a positive attitude • willingness of all staff and management to work with family/whānau as a team • flexibility to meet changing needs *Additional bullet point* • a culturally responsive environment	C
3.4.4: Education for autistic students in Aotearoa New Zealand schools should have the following elements: • individualised supports and services • systematic instruction • comprehensible and structured learning environments • specialised curriculum content • a functional approach to 'behaviours of concern' • family/whānau involvement *Additional bullet point* • culturally responsive approaches	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. *Changed to:* Prior to commencing a new supportive approach, gather detailed information on behavioural, emotional and mental health difficulties, address differential diagnosis, screen for medical conditions, and address cultural and environmental issues.	B

Revised recommendations and Good Practice Points	Grade
4.1.5: Treatment plans should be comprehensive, and include behavioural needs, educational interventions, psychosocial approaches, communication, environmental and systems issues, and the suitability (or not) of medication. *Changed to:* Support plans should be comprehensive, and include behavioural needs, educational supports, psychosocial approaches, communication, environmental, cultural and systems issues, and the suitability (or not) of medication.	B
4.8.2: People with ASD experiencing serious mental health disorders should be supported by mental health services appropriate to their age or situation. *Changed to:* **4.8.2:** People on the autism spectrum experiencing serious mental health disorders should be supported by mental health services appropriate to their age, situation, and culture.	✓
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:	C
• focus on individual choice and preference, including strengths, capacities, interests and experiences	B
• include recognition that autistic people have a right to privacy, and a right to be autistic.	C
Changed to: 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:	C
• focus on individual choice and preference, including strengths, capacities, interests, and experiences	B
• include recognition that people on the autism spectrum have a right to privacy, a right to culturally responsive services, and a right to be autistic.	C
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 autism/takiwātanga. **Additional text**: this GPP is also relevant to Part 1 of the Guideline relating to diagnosis and initial assessment.	✓

New recommendations and Good Practice Points

New recommendations and Good Practice Points	Grade
1.1.5a: Diagnosticians should be aware of the potential for bias based on ethnicity which may lead to delayed diagnosis or misdiagnosis.	B
3.2.1.5a: When assessing immigrants and others where English is not their first language, it is important that interpreters and translators are available. **Rationale:** this sentence is in the Guideline after introducing Recommendation 3.2.1.5 and is considered to be important to highlight more prominently through a GPP.	✓
3.2.1.10a: Supports should be culturally responsive for the child or young person. **Rationale**: This is to recognise that the altered Recommendation3.1.11 is also relevant to the school years, and not just early childhood.	✓
4.1.5a: Supports should be accessible and appropriate to people from ethnic minority communities. This will require proactive measures. **Additional text**: Proactive measures are evidenced by individuals and organisations: • seeking advice and feedback from members of minority cultures regarding their experiences and needs • identifying where modifications of standard approaches are required to respond to these needs • validating these modifications in collaboration with members of the minority culture • undertaking to ensure that culturally responsive practices and measures become integrated and standardised within their own practice, and that of the organisation they represent • ensuring that barriers to full participation, including training and employment, of members of minority cultures within the organisation are eliminated, and replaced with strategies that enhance participation.	B
4.1.5b: Professionals should collaborate with individuals on the autism spectrum and their families/whānau to set culturally responsive goals.	✓
4.1.5c: Professionals, when working with people of other ethnicities, should reflect on their own cultural beliefs and experiences and how these influence their practice.	✓

New recommendations and Good Practice Points	Grade
5.1.2a: Services for young people and adults on the autism spectrum should be accessible and appropriate to their ethnicity. This will require proactive strategies. **Additional text**: Proactive strategies are evidenced by individuals and organisations: • seeking advice and feedback from members of minority cultures regarding their experiences and needs • identifying where modifications of standard approaches are required to respond to these needs • validating these modifications in collaboration with members of the minority culture • undertaking to ensure that culturally responsive practices and measures become integrated and standardised within their practice, and that of the organisation they represent • ensuring that barriers to full participation, including training and employment, of members of minority cultures within the organisation, are eliminated, and replaced with strategies that enhance participation.	C
6.24a: Professionals working with people on the autism spectrum and their families/whānau need professional learning and development in cultural responsiveness, particularly the impact of ethnic culture on practice.	B

3.9 Summary of Supplementary Paper on the effectiveness of sexuality education for young people on the autism spectrum

Preamble

The review relates to the effectiveness of programmes aimed at providing education, training, and/or support relevant to sexual development, sexual health, and sexuality for adolescents and young adults on the autism spectrum. Sexuality includes sexual understanding and sociosexual knowledge, sexual identity and orientation, sexual expression, desire, and behaviour. Programmes were those which target adolescents and young adults on the autism spectrum either directly or indirectly through their family members, carers, clinicians, educators, and service providers.

Excluded from critical appraisal were programmes related to sexual abuse and sexual behaviour as side effects of medication.

Living Group process

The review updated evidence published from 2004 onwards relating to sexuality education for young people on the autism spectrum. The LGG identified this topic as an area worthy of updating and one which could lead to revised or additional recommendations in the Guideline.

The appraised body of evidence consisted of 12 studies: 3 guidelines, 2 systematic reviews, and 7 primary studies. Of the primary studies, 6 were case series studies with before-and-after programme assessments, and one was a randomised controlled trial, representing higher-order evidence.

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 Whaikaha – Ministry of Disabled People's website.[23]

New recommendations and Good Practice Points

New recommendations and Good Practice Points	Grade
3.2.2.6a: Tailored sexuality education, particularly when delivered individually and intensively, should be considered for young people on the autism spectrum. **Additional text:** It is not currently possible to recommend the content, components, and teaching strategies of sexuality educational programmes for young people on the autism spectrum. More research is needed. However, aspects found to be helpful in relation to cognitive behaviour therapy (CBT) may also be applicable to sexuality education (*see Recommendation 4.3.10a*). It should be noted that whilst the research in the current review related to adolescents, gender identity and sexuality is expressed throughout the lifespan and targeted sexuality education may also be useful for older people on the autism spectrum. **LGG Rationale**: Given the social and communication challenges associated with autism/takiwātanga, people on the spectrum can misinterpret social cues and language and have a greater openness about sexuality and sexual behaviour. This can sometimes lead to vulnerable situations or 'behaviours of concern' for people on the autism spectrum. Sexuality education programmes aim to encourage consent, healthy sexual development, reduce the risk of 'behaviours of concern', and reduce the risk of exploitation, abuse, and victimisation. There is evidence that sexuality education programmes that are tailored to people on the autism spectrum can improve psychosexual knowledge, at least in the short term.	B
3.2.2.7a (and also **6.24b**): All those who support young people and adults on the autism spectrum should be sensitive to gender and sexual diversity.	✓

New recommendations and Good Practice Points	Grade
3.2.2.7b: Sexuality education programmes in Aotearoa New Zealand need to be responsive to the cultural and linguistic diversity of their participants.	✓
3.2.2.7c: Aotearoa New Zealand research is needed to develop and evaluate sexuality education programmes for young people on the autism spectrum.	✓
3.2.2.7d: Decisions about participating in sexuality education should be guided by whether a person on the autism spectrum values it, and whether they are expected to benefit from it. **Additional text**: Caveat: This does not refer to situations where an alternative programme is required to target illegal or harmful behaviour. The textual reference to the new Recommendation and GPPs above is best cited within Part 3, section 3.2.b 'Social development of the Guideline', under a new subheading 'Sexuality education' following the subsection called 'The Hidden Curriculum' in which the need to teach skills in personal hygiene is referred.	✓

3.10 Summary of Supplementary paper on the effectiveness of strategies for supporting school transitions for young people on the autism spectrum

Preamble

The review covered supports aimed to improve transitions from preschool to primary school, and from primary school to intermediate (middle) and/or secondary school, as well as between year levels within schools.

'Preschool' refers to teacher-led, early childhood education centres, including kindergartens, preschools, and early support developmental programmes. Teacher-led means where 50% of the supervising adults must be qualified and registered as Early Childhood Education teachers. Note that in Aotearoa New Zealand, the term kindergarten is used to refer to state-funded, pre-school early childhood education services that are teacher-led.

'School' includes teacher-led State/public schools, kura kaupapa Māori schools, State integrated schools, and private/ independent schools offering education at the primary, intermediate or secondary level. Included are special residential schools or mainstream schools with attached learning support units or outreach services.

The review excluded transitions to, and from, parent-led childcare and schooling arrangements such as homeschooling, correspondence school/Te Kura, play centres/Kōhanga Reo, and playgroups/ Puna kōhungahunga. It also excluded transitions to post-secondary school environments including employment, training, further education, and/or independent living.

Living Group process

The review updated evidence published from 2004 onwards relating to the effectiveness of supports that aim to improve transitions for children and adolescents on the autism spectrum when commencing school or changing schools or year levels. The LGG identified this topic as an area worthy of updating and one which could lead to revised or additional recommendations in the Guideline.

The appraised body of evidence consisted of 26 studies: one clinical practice guideline, two systematic reviews, and 23 primary studies collecting original data. This update was informed by a systematic review updating the evidence for effective strategies for improving school transitions for children and young people. This review benefitted from the work of Nuske et al (2018)[452] which provided an initial coding framework of strategies for the current review's thematic analysis.

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 Whaikaha – Ministry of Disabled People's website.[24]

Revised recommendations and Good Practice Points

Revised recommendations and Good Practice Points	Grade
3.3.3: A quiet place should be provided for the young person to take a break from the busy environment of secondary school. *Unchanged* **Rationale**: Recommendation and GPP were left unchanged as they remain accurate and relevant to secondary students in the context of section 3.3: Particular issues relevant to secondary students. Recommendation 3.4.5 (revised, see below) provides more specific, extended guidance on transitions in all school settings which are also relevant here. **Additional text:** In the conclusion of the subsection titled "Transitions" add text to complete the current final sentence to become: "for further discussion about transitions see Part 3, section 3.4: Education sector organisation and management, and specifically Recommendation 3.4.5".	✓

Revised recommendations and Good Practice Points	Grade
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
Changed to:	
3.4.5: All transitions for students on the autism spectrum should be carefully planned and include the following: • Identifying a key education professional early in the transition process to guide children and young people and their family/whānau, and provide an ongoing point of contact. • Person-centred planning involving children and young people in decisions about the transition, respecting their views, and individualising their plans. • Having team transition planning meeting/s, preferably beginning 6–12 months prior to transition, involving family/whānau, key staff from both sending and receiving schools, and other supporting team members. • Developing a student profile in collaboration with the child/young person and their family/whānau to inform current and future school teams. The profile should include the child/young person's strengths, interests, needs, behaviours, preferences, and successful strategies. • Having transition visits for the child/young person to their new school environment to provide familiarisation, establish relationships, and alleviate anxiety. • Using visual supports appropriate to individual needs, for example: – a map of the new school – photographs, pictures, and social stories, possibly incorporated into an induction booklet – visual schedules, including calendars, timetables, diaries, and planners that present the routines of each day – providing social supports and environmental adaptations such as a safe person, peer buddy, adult mentors, and a safe space – having regular, constructive, culturally appropriate, and respectful communication between teachers and family/whānau – sharing support strategies across school and home environments.	B

Revised recommendations and Good Practice Points	Grade
Additional text: research that forms the basis of this updated recommendation relates to transitions to and between primary, intermediate and secondary schools and school levels. See Part 5, section 5.1 relating to post-secondary school transitions. Transitions into or from non teacher-led education settings (such as home-schooling) were not within the scope of this topic update. However, strategies suggested in Recommendation 3.4.5 are likely to be useful and should be considered by school staff and whānau in such situations. Research on social skills groups for young people and adults was updated as part of the Living Guideline process. It is summarised in Appendix 3.6, and is available as full text from Whaikaha – Ministry of Disabled People's website. (*Also see new Recommendation 4.2.1a, and new Good Practice Points 4.2.1b and 4.2.1c in Part 4.*) With respect to cultural appropriateness, research on the effects of ethnicity on recognition, diagnosis, education, mental health, and other support for people on the autism spectrum was also updated as part of the Living Guideline process. It is available from Whaikaha – Ministry of Disabled People's website. Note also that safe spaces are recommended in Recommendation 3.3.1.	

New Good Practice Point

New recommendations and Good Practice Points	Grade
3.4.5a: Many strategies recommended in Recommendation 3.4.5 are applicable to within-school transitions (e.g., between year levels and other transitions).	✓

3.11 Summary of Supplementary Paper on the effectiveness of physical activity interventions for young people on the autism spectrum

Preamble

This paper was informed by a systematic review updating the evidence for the effectiveness of physical activity interventions for people on the autism spectrum.

Physical activity interventions involve repeated gross-motor movements requiring physical exertion. In the current review, these are defined as planned, structured, repetitive, and purposeful.

The health benefits of physical exercise for virtually everyone are irrefutable and well established across many domains.[453] Regular physical activity is an effective primary and secondary preventative strategy for more than 25 chronic medical conditions with common risk reductions of 20%–30%.[454]

People on the autism spectrum are less likely to engage in physical activity, and are at greater risk for the development of obesity.[455, 456] Whilst many risk factors for chronic medical conditions are likely the same, individuals on the autism spectrum who often have co-occurring conditions may be more susceptible.

Living Group process

The review updated evidence published from 2004 onwards relating to the effectiveness of physical activity interventions for people on the autism spectrum.

The appraised body of evidence consisted of 14 studies: nine systematic reviews, and five primary studies collecting original data.

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 Whaikaha – Ministry of Disabled People's website.[25]

New recommendations and Good Practice Points

New recommendations and Good Practice Points	Grade
2.3.9a: Physical activities provide benefits across social, cognitive, and behavioural domains in addition to general well-being and should be considered for children and young people on the autism spectrum. **Rationale**: There is consistent evidence that physical activity interventions appear to show significant improvements on social functioning outcomes such as social interaction skills. Cognitive functioning and behavioural functioning measures are also improved in most studies evaluating outcomes in these domains. **Additional text:** Although the existing evidence related primarily to children and young people, it is likely to apply to adults. **Rationale**: Three of the appraised systematic reviews[457-459] did not have an age restriction for included studies, and included study participants aged up to 25 years.	B
2.3.9b: When supporting individuals participating in a physical activity or programme, their preferences should be respected, and needs accommodated. **2.3.9c:** Further research that targets meaningful outcomes for the autistic community is essential. **Rationale**: Research outcomes to date have primarily focused on addressing characteristics key to the diagnosis of autism/takiwātanga. However, there is increasing demand from the autistic community for research into outcomes that are important to them. It is unclear the extent to which the reviewed research outcomes meet these expectations.	✓ ✓
4.1.5d: Further research that targets meaningful outcomes for the autistic community is essential. **Rationale**: It is recognised that whilst Good Practice Point 2.3.9c was developed in response to the research considered in the review of physical activity interventions, it was also relevant to other research in the Guideline, and particularly to that presented in Part 4. For this reason, the Good Practice Point is also presented prominently in Part 4's summary of recommendations in its Introduction section.	✓

3.12 Summary of Supplementary Paper on the effectiveness of music therapy for children and young people on the autism spectrum

Preamble

There is a growing body of evidence that music therapy can provide benefits across several domains for children on the autism spectrum, particularly concerning social communication.

In this review, music therapy is defined as the planned use of musical experiences and the relationships that develop through them for therapeutic goals. Therapy is delivered in regular sessions to individuals or groups by a music therapist (or a person trained in music therapy techniques by a music therapist). Whilst no age restriction was applied, the results were principally related to children and young people on the autism spectrum.

It should be noted that this review and the LGG's recommendation do not relate to the value of music *per se*, or to supports where music is a component but where music therapy is not the core approach.

Living Group process

The current review updated evidence published from 2004 onwards relating to the effectiveness of music therapy for children and young people on the autism spectrum. The LGG identified this topic as an area worthy of updating and one which could lead to revised or additional recommendations in the Guideline.

The appraised body of evidence consisted of 11 studies: one clinical practice guideline, four systematic reviews, and seven primary studies (reporting on 6 trials) collecting original data.

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 Whaikaha – Ministry of Disabled People's website.[26]

New recommendation

New recommendation	Grade
4.5.2a: Music therapy can enhance social communication skills and should be considered for children and young people on the autism spectrum. **Rationale:** The LGG considered the body of evidence relating to the effectiveness of music therapy as measured in 6 trials appraised in the current review, in addition to 10 trials considered in the Cochrane systematic review and meta-analysis.[460] The original Guideline noted that "no large scale randomised control trial involving young autistic children has been conducted". Since then there has been a significant number of trials, including the large Time-A multi-centre trial.[461] The authors of this significant trial, conducted across 9 countries and involving 365 young autistic children, reported that it "did not support the use of improvisational music therapy for symptom reduction in children on the autism spectrum" (p. 525). This conclusion was based on a lack of a significant effect on its primary outcome measure which was a diagnostic instrument (ADOS). The LGG considered that this measure may not be sensitive to change or reflect outcomes that are important to people on the autism spectrum. The trial was also limited in that children in the comparative 'enhanced usual care' arm tended to receive more hours of other established concomitant therapies (such as speech and language therapy, communication training, occupational therapy, and physical therapy) than the music therapy group. Considering the evidence base as a whole, particularly its limitations concerning choice of outcome measures and heterogeneity of samples and supports, the LGG considered that there was sufficient evidence to recommend music therapy for children and young people on the autism spectrum. However, the mixed findings across trials led to this recommendation being graded as a B rather than an A. In terms of placement of the recommendation within the Guideline, music therapy was originally referenced briefly in the original Guideline in Part 3: Education for learners, under Part 3, section 3.2.c relating Sensorimotor development. However, the LGG decided that the new Recommendation was more appropriately referenced within Part 4, within section 4.5 relating to 'Other approaches'. **Additional text:** A cross-reference to this Recommendation is also provided in Part 3 *(under section 3.2.c: Sensorimotor development)*, and in Appendix 8, where music therapy is discussed within a broader overview of educational approaches.	B

3.13 Summary of Supplementary Paper on the effectiveness of supports for autistic students in tertiary education

Preamble

There is a growing awareness that universities and colleges should make themselves more supportive environments for people across a wide range of neurodiversity, cultural backgrounds, learning preferences, and mental health needs. This includes the promotion of an accessible environment that facilitates autistic students to reach their potential and flourish within tertiary education and beyond.

Autistic people/tāngata whaitakiwātanga have the right to access appropriate student services so they can complete and succeed in their tertiary education under the United Nations Convention on the Rights of Persons with Disabilities and the Tertiary Education Strategy (TES). To recognise this, from 2022, the Tertiary Education Commission (TEC)[375] requires all publicly funded providers to develop Disability Action Plans (DAPs) using the Kia Ōrite toolkit[376] to ensure they meet their responsibilities. As part of this planning, and to give effect to the new Code (Education Pastoral Care of Tertiary and International Learners) Code of Practice 2021)[377] that came into effect from 1 January 2022, tertiary education providers are required to involve learners and their communities in developing their strategic goals and plans for learners' safety and well-being. To meet the range of needs of autistic learners, providers should actively include the views of autistic learners.

Living Group process

The current review updated evidence published from 2004 onwards relating to the effectiveness of supports for autistic students in tertiary education. The LGG identified this topic as an area worthy of updating and one which could lead to revised or additional recommendations in the Guideline.

The appraised body of evidence consisted of 17 studies: one clinical practice guideline, four systematic reviews one of which included 5 eligible primary studies evaluating peer mentor programmes, and 13 primary studies collecting original data.

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 Whaikaha – Ministry of Disabled People's website.[27]

See also the excellent guides produced by Altogether Autism for the Tertiary Education Commission (https://www.altogetherautism.org.nz/supporting-autistic-tertiary-learners/).

Revised recommendation

Revised recommendation	Grade
5.1.6 and 6.10a: Tertiary education providers should ensure that their teaching and support staff are aware of the range of educational and wellbeing needs of autistic students, and available accommodations and supports. **Rationale:** The diversity of uptake and preferences for these supports is indicative of the heterogeneous needs of autistic students. That in itself brings home the scope of the challenge faced by disability support officers in tailoring services to individuals.[462]	C

New recommendations and Good Practice Points

New recommendations and Good Practice Points	Grade
5.1.5: Tertiary education providers should work with autistic students to identify and implement accommodations that meet their learning and assessment needs. Effective approaches include offering: • extended assessment times • flexible assessment formats and testing environments • recorded lectures • lecture notes • support services staff liaison • tutoring • flexible course loads.	B
5.1.7: Tertiary education providers should be proactive in identifying autistic students and in implementing supports for their mental-health and wellbeing. Multi-component approaches are most effective, and include the following components: • peer mentoring and trained professional mentoring • fostering social connection through organised, recreational activities with peers • counselling, psychological therapy and psychosocial support • problem solving, goal setting, practical life skills, and organisational skills.	B
5.1.7a: Tertiary education supports for autistic students should be easy to access, flexible, individualised, culturally responsive, and mana-enhancing.	✓
5.1.7b: Recognising that some autistic/takiwātanga students may not be formally diagnosed or wish to disclose their diagnosis, tertiary education providers should promote access to academic accommodations and support services.	✓
5.1.7c: Not all autistic individuals consider themselves to be disabled. Tertiary education providers should consider using an alternative name for their student disability services that is more inclusive (e.g., Student Accessibility Service).	✓

Appendix 4: Diagnostic criteria for ASD

(DSM-IV-TR, ICD-11, and DSM-5)

4.1 DSM-IV-TR

Note: DSM-IV-TR[30] criteria were revised in the latest version of the Diagnostic and Statistical Manual for Mental Disorders, the DSM-5.[29] The implications of the DSM-5 for the Guideline were considered by the Living Guideline Group in their Supplementary Paper,[19] which is summarised in Appendix 3.5. A summary of differences between DSM-IV[30] and DSM-5[29] are presented in section 4.3 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 the developmental level

      (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., 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 the 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) inflexible adherence to specific, non-functional routines or rituals

      (c) stereotyped and repetitive motor mannerisms (e.g., 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 the developmental level

(3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., 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) inflexible adherence to specific, non-functional routines or rituals

(3) stereotyped and repetitive motor mannerisms (e.g., 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 (e.g., 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 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 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, subthreshold symptomatology, or all of these.

The diagnostic criteria for DSM-IV-TR[30] have been reprinted with permission from the American Psychiatric Association.

4.2 ICD-11

The World Health Organization's (WHO) new International Classification of Diseases (ICD-11)11 came into effect on 1 January 2022.[39]

6A02 Autism Spectrum Disorder

Autism spectrum disorder is characterised by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual's age and sociocultural context. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities.

Includes: autistic disorder

Excludes: Rett syndrome (LD90.4)

Diagnostic Requirements

Essential (Required) Features:

Persistent deficits in initiating and sustaining social communication and reciprocal social interactions that are outside the expected range of typical functioning given the individual's age and level of intellectual development. Specific manifestations of these deficits vary according to chronological age, verbal and intellectual ability, and disorder severity. Manifestations may include limitations in the following:

- Understanding of, interest in, or inappropriate responses to the verbal or non-verbal social communications of others.
- Integration of spoken language with typical complimentary non-verbal cues, such as eye contact, gestures, facial expressions and body language. These non-verbal behaviours may also be reduced in frequency or intensity.
- Understanding and use of language in social contexts and ability to initiate and sustain reciprocal social conversations.
- Social awareness, leading to behaviour that is not appropriately modulated according to the social context.

- Ability to imagine and respond to the feelings, emotional states, and attitudes of others.
- Mutual sharing of interests.
- Ability to make and sustain typical peer relationships.

Persistent restricted, repetitive, and inflexible patterns of behaviour, interests, or activities that are clearly atypical or excessive for the individual's age and sociocultural context. These may include:

- Lack of adaptability to new experiences and circumstances, with associated distress, that can be evoked by trivial changes to a familiar environment or in response to unanticipated events.
- Inflexible adherence to particular routines; for example, these may be geographic such as following familiar routes, or may require precise timing such as mealtimes or transport.
- Excessive adherence to rules (e.g., when playing games).
- Excessive and persistent ritualized patterns of behaviour (e.g., preoccupation with lining up or sorting objects in a particular way) that serve no apparent external purpose.
- Repetitive and stereotyped motor movements, such as whole body movements (e.g., rocking), atypical gait (e.g., walking on tiptoes), unusual hand or finger movements and posturing. These behaviours are particularly common during early childhood.
- Persistent preoccupation with one or more special interests, parts of objects, or specific types of stimuli (including media) or an unusually strong attachment to particular objects (excluding typical comforters).
- Lifelong excessive and persistent hypersensitivity or hyposensitivity to sensory stimuli or unusual interest in a sensory stimulus, which may include actual or anticipated sounds, light, textures (especially clothing and food), odors and tastes, heat, cold, or pain.

The onset of the disorder occurs during the developmental period, typically in early childhood, but characteristic symptoms may not become fully manifest until later, when social demands exceed limited capacities.

The symptoms result in significant impairment in personal, family, social, educational, occupational or other important areas of functioning. Some individuals with Autism Spectrum Disorder are able to function adequately in many contexts through exceptional effort, such that their deficits may not be apparent to others. A diagnosis of Autism Spectrum Disorder is still appropriate in such cases.

Specifiers for characterizing features within the Autism Spectrum:

These specifiers enable the identification of co-occurring limitations in intellectual and functional language abilities, which are important factors in the appropriate individualization of support, selection of interventions, and treatment planning for individuals with Autism Spectrum Disorder. A qualifier is also provided for loss of previously acquired skills, which is a feature of the developmental history of a small proportion of individuals with Autism Spectrum Disorder.

Co-occurring Disorder of Intellectual Development

Individuals with Autism Spectrum Disorder may exhibit limitations in intellectual abilities. If present, a separate diagnosis of Disorder of Intellectual Development should be assigned, using the appropriate category to designate severity (i.e., Mild, Moderate, Severe, Profound, Provisional). Because social deficits are a core feature of Autism Spectrum Disorder, the assessment of adaptive behaviour as a part of the diagnosis of a co-occurring Disorder of Intellectual Development should place greater emphasis on the intellectual, conceptual, and practical domains of adaptive functioning than on social skills.

Qualifiers should be applied to indicate the presence of absence of a co-occurring Disorder of Intellectual Development:

- without Disorder of Intellectual Development
- with Disorder of Intellectual Development

Degree of Functional Language Impairment

The degree of impairment in functional language (spoken or signed) should be designated with a second qualifier. Functional language refers to the capacity of the individual to use language for instrumental purposes (e.g., to express personal needs and desires). This qualifier is intended to reflect primarily the verbal and non-verbal expressive language deficits present in some individuals with Autism Spectrum Disorder and not the pragmatic language deficits that are a core feature of Autism Spectrum Disorder.

The following qualifier should be applied to indicate the extent of functional language impairment (spoken or signed) relative to the individual's age:

- with mild or no impairment of functional language
- with impaired functional language (i.e., not able to use more than single words or simple phrases)
- with complete, or almost complete, absence of functional language

Application of codes for the specifiers above leads to the following diagnostic codes:

6A02.0 ASD with mild or no impairment of functional language, and without Disorder of Intellectual Development

6A02.1 ASD with mild or no impairment of functional language, and with Disorder of Intellectual Development

6A02.2 ASD with impaired functional language, and without Disorder of Intellectual Development

6A02.3 ASD with impaired functional language, and with Disorder of Intellectual Development

6A02.5 ASD with complete, or almost complete, absence of functional language, and with Disorder of Intellectual Development

6A02.Y Other Specified Autism Spectrum Disorder can be used if the above parameters do not apply.

6A02.Z Autism Spectrum Disorder, Unspecified can be used if the above parameters are unknown.

Loss of Previously Acquired Skills

A small proportion of individuals with Autism Spectrum Disorder may present with a loss of previously acquired skills. This regression typically occurs during the second year of life and most often involves language use and social responsiveness. Loss of previously acquired skills is rarely observed after 3 years of age. If it occurs after age 3, it is more likely to involve loss of cognitive and adaptive skills (e.g., loss of bowel and bladder control, impaired sleep), regression of language and social abilities, as well as increasing emotional and behavioural disturbances.

There are two alternative specifiers:

- **6A02.x0** without loss of previously acquired skills
- **6A02.x1** with loss of previously acquired skills

Autism Europe comments on how the changes in ICD-11 bring the diagnostic criteria for autism closer in line with that of the DSM-5.[29] The ICD-11 "includes Asperger's Syndrome, Childhood Disintegrative Disorder and certain other generalised developmental disorders, within the category of 'Autism'".

4.3 DSM-5

Implications of the DSM-5[29] revised criteria for the original Guideline were considered by the Living Guideline Group in its Supplementary Paper (see Appendix 3.5).[19]

The following table summarises the differences between DSM-IV-TR[21] and DSM-5[29] Criteria for ASD, and are adapted from Halfon & Kuo (2003).[463]

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
Social Interaction Domain (minimum required: ≥2 of 4)	**Social Interaction and Social Communication (minimum required: all 3)**
1A. Marked impairments in the use of multiple nonverbal behaviours to regulate social interaction	**A2.** Deficits in nonverbal communicative behaviours used for social interaction
1B. Failure to develop peer relationships appropriate to developmental level	**A3.** Deficits in developing and maintaining relationships appropriate to developmental level
1C. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people	(*Subsumed into* ***A1***)
1D. Lack of social or emotional reciprocity	**A1.** Deficits in social emotional reciprocity
Communication Domain (minimum required: ≥2 of 4)	**Social Interaction and Social Communication (minimum required: all 3)**
2A. Delay in, or total lack of, the ability to use spoken language	(*Criterion removed*)
2B. Marked impairment in the ability to initiate or sustain a conversation with others	(*Subsumed into* ***A1***)
2C. Stereotyped or repetitive use of language or idiosyncratic language	(*Subsumed into* ***B1***)
2D. Lack of varied, spontaneous make-believe or social imitative play appropriate to developmental level	(*Subsumed into* ***A3***)

DSM-IV-R: Autistic Disorder	DSM-5: Autism Spectrum Disorder
Restricted Interests and Repetitive Behaviours Domain (minimum: ≥1 of 4)	**Restricted Interests and Repetitive Behaviours Domain (minimum required: ≥2 of 4)**
3A. Encompassing preoccupation with ≥1 stereotyped and restricted pattern of interest abnormal in intensity or focus	**B3.** Highly restricted fixated interests that are abnormal in intensity or focus
3B. Apparently inflexible adherence to specific routines or rituals	**B2.** Excessive adherence to routines, ritualised patterns of verbal or nonverbal behaviour, or excessive resistance to change
3C. Stereotyped and repetitive motor mannerisms	**B1.** Stereotyped or repetitive speech, motor movements, or use of objects
3D. A persistent preoccupation with parts of objects	(*Criterion removed or possibly subsumed into* ***B3***)
	B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment
	Additional criteria for DSM-5: Autism spectrum disorder
	C. Symptoms must be present in early childhood (but may not fully manifest until social demands exceed limited capacities)
	D. Symptoms together limit and impair everyday functioning
	E. 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 condition 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. 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 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 based on 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 analysed systematically all relevant evidence (2750 articles) published up to 1998.[464] 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 a 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
Sensitive and specific developmental screening instruments include: • Ages and Stages Questionnaire (ASQ) • BRIGANCE Screens • Child Development Inventories (CDI) • Parents’ Evaluations of Developmental Status (PEDS).	A
Autism-specific screening tools that have adequate sensitivity and specificity include: • Checklist for Autism in Toddlers (CHAT) • Autism Screening Questionnaire (ASQ).	B
Diagnostic tools for autism that have been shown to have adequate sensitivity and specificity include the following: • 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. • Parent Interview for Autism (PIA). This is a structured interview with 118 items that takes 45 minutes to deliver. • Autism Diagnostic Interview-Revised (ADI-R). This is currently one of the two best available reference points for the diagnosis of ASD. It is a comprehensive structured parent interview that takes one hour to deliver, with specific training and validation procedures. • Childhood Autism Rating Scale (CARS). This is a structured interview and observations with 15 items, designed for children > 24 months, which takes 30–45 minutes to deliver. • 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 cut-off scores and takes 30 to 45 minutes to deliver.	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[71] 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 Aotearoa New Zealand or Australian settings. Although some tools reported in the English language literature have been adapted and utilised in Chinese and Japanese populations, no reports exist of studies in Māori or Pacific populations. This represents a clear opportunity for Aotearoa New Zealand to do this work.

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 or ICD 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 any cost analyses are comparing diagnostic tools with clinician assessments 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 autistic individuals improve outcomes?
2. Does performing a baseline cognitive assessment in individuals diagnosed with ASD enable more effective planning of a 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 based on 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 several different study designs: reviews, guidelines, cohort studies (of groups of ‘higher functioning’ autistic children who had cognitive tests at baseline and follow-up) and studies of cognitive differences and styles in autism versus controls (either non-autistic 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 challenges are postulated to be at the core of the characteristics of autism observed (e.g., difficulties in executive functioning, weak central coherence).	C
Achievement level in formal tests of non-verbal cognition (i.e., 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 autistic individuals improve outcomes?**

   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 a programme and more efficient use of resources?**

   There is no evidence for or against this, but extrapolation from studies supports the conclusion that a better definition of learning skills and prognosis by cognitive assessment will assist in planning optimal supports.

   Expert supporting opinions 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 non-verbal problem-solving in ‘high functioning’ autistic individuals correlate with the outcome (whereas) the severity of autistic behaviours is a poor predictor of prognosis.[463]

   (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 an autistic child.

Cognitive ability also has an important role in prognosis and support 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 support 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 difficult to document significant social and communicative deficits below this age level.
- Treatment research generally has supported the notion that response to various supportive approaches has some relation to overall cognitive functioning.[465] For example, certain intensive behavioural approaches are 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.[69]

Appendix 7: Core elements of effective teaching of autistic individuals

In Appendix 7, the core elements of effective teaching described in Part 3, section 3.4: Education sector organisation and management, are expanded and tables show possible barriers and ways to implement these elements in the Aotearoa 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 the practice experience and knowledge of the Guideline Development Team from the education workstream.[241]

7.1 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's preferences and interests to determine the most appropriate intensity and level of instruction to meet their individual goals.

7–12 years	13–20 years
Incorporating the child's preferences and focused interests	
It is possible to include the student's preferences and focused interests into the learning objectives for teaching in almost any curriculum area in the primary area. Teachers must consider the student's skills and preferences when asking students to demonstrate their learning (e.g., the use of video and other technologies, rather than writing, which is often a difficult).	At this level, the actual content becomes more prescribed and more difficult to adapt. Therefore, teachers should: • give students options, such as courses within their interest studied by correspondence • consider flexible ways for students to demonstrate their knowledge • work with students to give them the social understanding to be able to interpret the achievement criteria.

7–12 years	13–20 years
Individual attention to the child's needs to determine intensity and level of instruction	
• 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. • Supports should use the student's strengths and find accommodations for their weaknesses to allow them to participate as much as possible. • It is essential that the student's stress levels are monitored and that planned down time is incorporated into a programme where necessary.	
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.	• Students do not need a goal for every subject. The key goals can be adapted and generalised across all subject areas. • At a certain point, adaptive behaviours may need to become the priority. • Children and young autistic people 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.

7.2 Systematic instruction

This involves careful 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.	
• Programmes need to set priorities with an emphasis on communication and social skills along with other ‘pivotal’ skills. • It is important that all instruction is well considered and goal directed.	• 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. • Provision may need to be made for a number of teachers to receive release for professional learning and development. • The emphasis needs to be on: – the student’s understanding of the aim of the task – getting step-by-step (visual) instructions – the social, communication and cognitive elements being transparent – student motivation and feedback.

7.3 Comprehensible and structured learning environments

This includes strategies such as organising the instructional setting, providing a schedule of activities that are 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 (e.g., 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 daily 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. Autistic students 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.

7.4 Specific curriculum content

This component describes prioritising the difficulties for autistic individuals key to an autism diagnosis related to the areas of communication and social interaction, and the skills that are required to participate.

7–12 years	13–20 years
Autistic children 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: • are most likely to be useful for the student to control his or her environment • will increase the student's independence and quality of life • will increase the student's competent performance. A goal for all students is to communicate effectively, even if the form is non-traditional.	
• There can be a tension in setting goals between the needs of the student and the needs of the teacher. • Communication and social interaction goals are clearly part of the key competencies in the Aotearoa New Zealand Curriculum. Teachers do not always have the skills to adapt and teach these competencies to autistic children. • All specialists and teachers who work with autistic students 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 and alternative communication (AAC), use of technology, PECS, pivotal response training, peer tutoring and social stories.	• 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. • Teachers and specialists need to work to find alternatives or accommodations that enhance participation in the student's environments. • 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. • 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.

7.5 Functional approach to 'behaviours of concern'

This describes the process by which the child's 'behaviour of concern' 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 Part 3 section 3.2.e: Self-management skills and addressing 'behaviours of concern' in education settings*).

Primary	Secondary
• 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. • Teachers, principals ,and boards of trustees need to examine their policies and discuss the potential for conflict. • The principles of functional behaviour assessment are not well understood by teachers and some specialists, and professional learning and development is needed.	

7.6 Family involvement

Primary	Secondary
Schools need: • policies and practices that make parents, family and whānau feel welcome and encourage them to participate • to support parents, family and whānau to get the information they need to make informed decisions • to adopt and support effective home–school communication systems.	
Systems are needed to help parents/caregivers/whānau 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 approaches

Background

The following educational programmes are currently being used within Aotearoa New Zealand or influence 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.[118, 149, 466]

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 Aotearoa 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[204] 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 ‘behaviours of concern’. The programme 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).[206]

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 on the child’s interests and choices.

The Incidental Teaching programme includes children in classrooms with non-autistic 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,[292] 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.[220] In 1998 the centre-based programme was closed and the Model was provided in the natural environments of the home and early childhood centres with non-autistic peers.

Play is used as the 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.[253] It has since been incorporated into the Denver school system. The programme includes autistic and non-autistic children in classrooms for 15 hours per week. The autistic child 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 emphasizes 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.[207] It is based on a variety of well-researched methodologies.

This comprehensive multidisciplinary model addresses the key challenges faced by autistic children. Support 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.[231] They involve written or drawn stories that 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.[255] The developmentally based model has 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.[209] 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 that support social development. The role and style of interactions of the 'partner' are key elements.

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, based on Son-Rise.[444] 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 how they interact with their 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.[467] It aims 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. It aims 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

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.[468]

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 autism

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 autism adapted with permission from CAMHSNET[469] and updated by Drs Matt Eggleston and Andrew Marshall (Chair and Deputy Chair of the Living Guideline Group)

Generic name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
Atypical Antipsychotics				
Risperidone	Oral liquid: 1mg/ml Tablet: 0.5mg, 1mg, 2mg, 3mg, 4mg Orally disintegrating tablets: 0.5mg, 1mg, 2mg Retail pharmacy – Specialist Fully subsidised	0.015mg/kg/day to 0.05mg/kg/day in two divided doses	• Weight gain • Extrapyramidal side effects (EPSE) (worse at higher dosage) • Akathisia (especially adolescents) • Tardive dyskinesia • Neuroleptic malignant syndrome • Sedation • Insomnia • Type 2 diabetes mellitus • Sialorrhoea • Enuresis, rhinitis, epistaxis • Sexual dysfunction, priapism	Carbamazepine (↓ levels of RISP) SSRIs, especially fluoxetine and others metabolised by P4502D6 (↑ levels of RISP)

Generic name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
Aripiprazole	Tablet: 5mg, 10mg, 15mg, 20mg, 30mg Retail pharmacy – Specialist Fully subsidised	2.5mg – 15mg	• As per risperidone but weight gain, EPSE and sedation less likely	Fewer than risperidone
Olanzapine	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. Maximum 20mg per day in adolescents>40kg	• As for risperidone, but weight gain and type 2 diabetes more likely and EPSE less likely	
Quetiapine	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, but sedation more likely	
Typical antipsychotics				
Haloperidol	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 Maximum 10mg/day	• EPSE very common • Tardive and withdrawal dyskinesias • Sedation	SSRIs (↑ level of haloperidol) Ginseng

Generic name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
Chlorpromazine	Tablet: 10mg; 25mg; 100mg Also injection Retail pharmacy Fully subsidised	0.25 to 5 mg/kg/day in 4 divided doses	• Sedation • Photosensitive rash • EPSE • Seizures, jaundice, agranulocytosis, cardiotoxicity (arrhythmias)	Propranolol Valproate
Selective serotonin re-uptake inhibitors (SSRIs)				
Fluoxetine	Tablet dispersible: 20mg Capsule: 20mg Retail pharmacy Fluox brand fully subsidised	0.15 to 0.6 mg/kg/day as a single dose	• Agitation, behavioural disinhibition • Anxiety • Dry mouth • Drowsiness • Nausea, weight loss • Lowered seizure threshold **Serotonin toxicity in overdose**	Wide range of drugs, especially those metabolized by P4502D6 St John's Wort **Risk of serotonin toxicity with other serotonergic drugs**
Paroxetine	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.	**Risk of serotonin toxicity with other serotonergic drugs**

Generic name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
Citalopram	Tablet: 20mg Retail pharmacy Fully subsidised	0.2 to 0.4 mg/kg/day as a single dose	As per fluoxetine	Fewer interactions than most other SSRIs but still risk of serotonin syndrome Venlafaxine MAOIs Buspirone MDMA (ecstasy) as high risk of **Serotonin toxicity**
Escitalopram	Tablet:10mg 20mg Retail Pharmacy Fully subsidised	0.1 to 0.2mg/kg/day as a single dose	As per fluoxetine	Fewer interactions than most other SSRIs but still risk of serotonin syndrome
Sertraline	Tablet: 50 or 100mg Retail pharmacy Fully subsidised	0.5 to 3 mg/kg/day as a single dose	As per fluoxetine	Tricyclic antidepressants and a wide range of drugs. **Risk of serotonin toxicity with other serotonergic drugs**

Generic name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
Stimulants and other ADHD medication				
Methylphenidate (Rubifen Ritalin Concerta)	Tablet: 5mg, 10mg, 20mg (immediate release – IR) – Rubifen Tablet: 20mg long acting – Rubifen SR, Capsule: Ritalin LA 10mg, 20mg, 30mg, 40mg Oro-dispersible tablet: Concerta: 18mg, 27mg, 36mg, 54mg Retail Pharmacy Special Authority – for full details see PHARMAC website. Only brands noted above are fully subsidised. Class A controlled drug.	Start low 2.5mg to 5mg per day as morning dose in younger children. Can increase up to 1 mg/kg/day. Maximum dose 60mg per day	• Anorexia • Irritability and emotional lability • Insomnia • Exacerbation of tic disorder • Rebound hyperactivity • Exacerbation of repetitive or obsessive compulsive behaviour	Carbamazepine
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 in younger children. Can increase up to 1mg/kg/day. Maximum dose 40mg per day	• Anorexia • Irritability and emotional lability • Insomnia • Exacerbation of tic disorder • Rebound hyperactivity • Exacerbation of repetitive or obsessive compulsive behaviour	• Acetazolamide • Sodium bicarbonate

Generic name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
Atomoxetine	Capsules: 10mg, 18mg, 25mg, 40mg, 60mg, 80mg and 100mg Retail pharmacy Fully subsidised	0.5mg – 1.4mg/kg (children and adolescents up to 70kg) 40mg – 100mg (children and adolescents over 70kg and adults)	• Tachycardia, hypertension • Headache • Insomnia • Dry mouth • Decreased in appetite • Nausea, vomiting and abdominal pain • Somnolence and sedation	MAOIs
Clonidine	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	• Sedation • Hypotension **(Monitor blood pressure)** • Depression • Withdrawal hypertension (taper over 6 days) • Precocious puberty – rare	Previous concerns about interaction with Methylphenidate have not been proven.
Other drugs				
Melatonin	Tablet: 2mg controlled release Special Authority for young people up to 18 years	2mg-6mg mg at night	• Sedation	

Generic name	NZ prescribing information	Recommended dose range	Adverse effects	Important interactions
Promethazine	Oral liquid: 5mg/5ml Tablet: 10mg; 25mg Retail pharmacy Part subsidy on liquid Fully subsidised tablet formulations		• Sedation • Paradoxical agitation	

Note: Information is correct at the time of writing. Brands available and subsidy status are under constant review. Prescribers should check current information on the PHARMAC (www.pharmac.govt.nz) and MEDSAFE (www.medsafe.govt.nz) websites.

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“Whaowhia te kete matauranga”

Fill the basket of knowledge

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