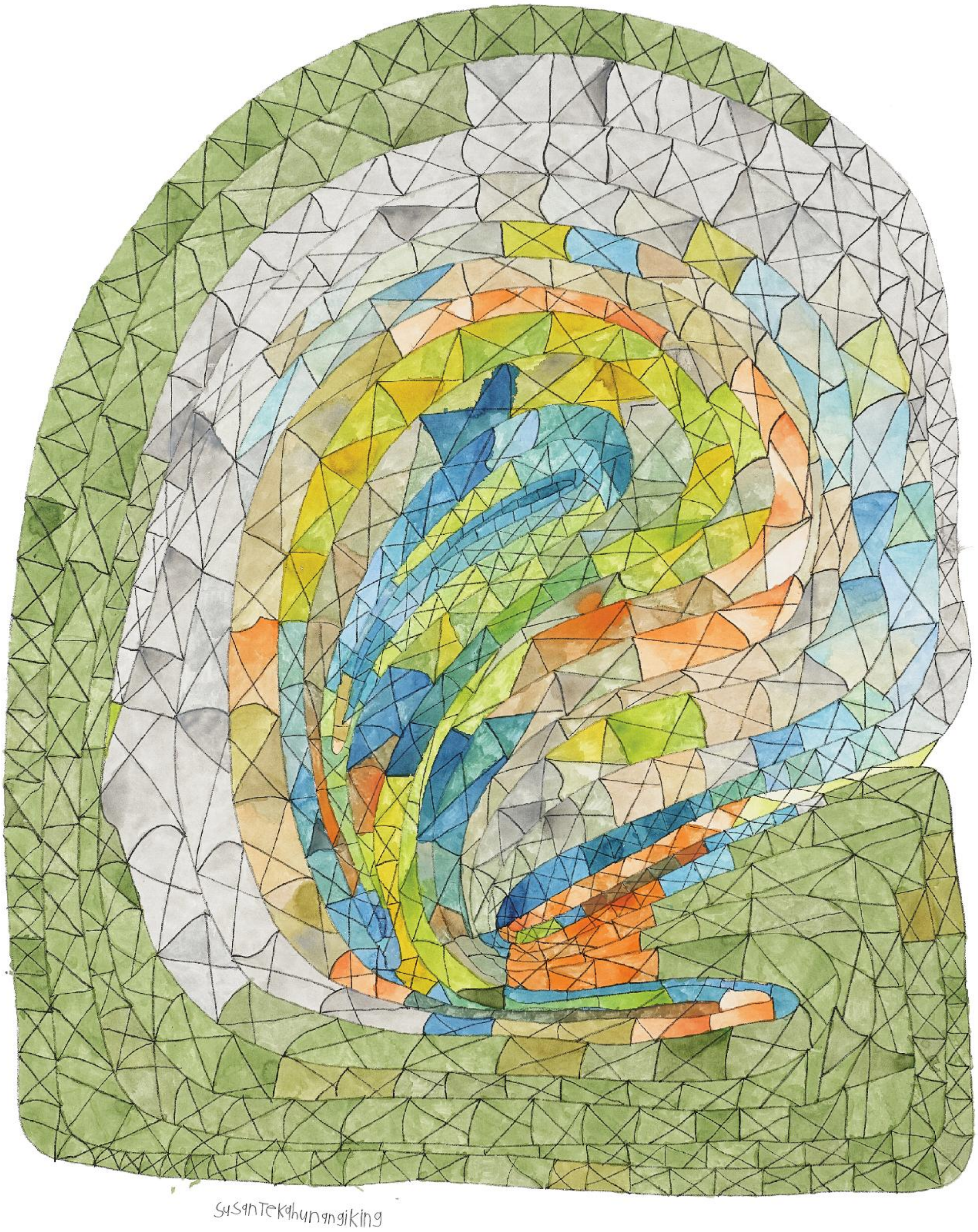


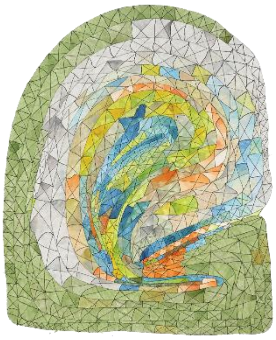
Whaikaha
Ministry of
Disabled People

Aotearoa New Zealand **Autism Guideline:**

He Waka Huia Takiwātanga Rau

Summary

Third Edition



Cover artwork by Susan Te Kahurangi King
Untitled 11, 2022, edition of six hand-coloured lithographs, 1093 x 775 mm.

About the Artist

Source: APS Editions (photographed by Samuel Hartnett)

Susan Te Kahurangi King, born 1951 in Te Aroha, has been creating extraordinary drawings prolifically 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 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 mo te ingoa

A word of explanation about the title

He Waka Huia Takiwātanga Rua

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

Voices

Autistic people/tāngata whaitakiwātanga and their families/whanau

“After diagnosis, there is often a ‘black hole’ for families.” [4]

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

“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.” [6]

“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.” [7]

“Parents become highly educated – of necessity, not of choice.” [2]

“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.” [8]

Voices

“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.” [3]

“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.” [8]

“I am tired of having to do 100% of the changing, and there is no change with most people without autism.” [3]

“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.” [8]

“I am sick of social skills groups … Why can’t someone go to the bar with me or to chess club?” [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.” [3]

“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]

Voices

"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." [9]

"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]

"I am proud of who I am and autism is part of who I am. In fact, I can't separate the autism from what I do, think or am." [1]

"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]

Contents

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.

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,[14] 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, choice and control over the supports which enable them to thrive, flourish and live the life they want.

About the Aotearoa New Zealand Autism Guideline

Background

The term ASD (Autism Spectrum Disorder) is the diagnostic term used to refer to a condition that affects communication, social interaction, and adaptive behaviour. The spectrum of autism is now recognised as covering a wide range of support needs, disabilities, communication abilities and intellectual ability.

As specified in the current version of the Diagnostic and Statistical Manual for Mental Disorders, the DSM 5,[15] 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.

These features cause significant impacts in social, occupational, or other important areas of current daily living, although their intensity may vary. The diverse support needs if people across the autism spectrum require that a wide range of services and approaches be employed.

There is no definitive information on the prevalence and incidence of autism in Aotearoa New Zealand. However, considering a range of estimates[16], 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.

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.

Guideline development process

Background to the first edition

As the first autism Guideline in Aotearoa New Zealand, this resource provides evidence-based information for disability, health, and education professionals and social service agencies who support autistic people, their families and whānau.

In 1998, the Government commissioned a review of autism services, now known as the Curry Report, across key sectors. In 2002, in response to recommendations, the Ministry of Health and the Ministry of Education, in conjunction with the Paediatric Society of New Zealand started work on scoping an Autism Guideline. In December 2002, a Steering Group was set up to help guide the work of the guideline project team. It included representation from: autistic adults, parents/families of autistic people, professional clinician groups, support services, educators, Pacific advisers, early intervention services, and the Ministries of Health and Education. A Cross Government Officials Group oversaw the development of the original Guideline and provided regular updates for their respective Ministers.

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 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. **Part 7** and **Part 8** cover the perspectives and experiences of Māori and Pacific people on the autism spectrum, respectively, and explore issues of information needs, diagnosis, assessment, support, access, services and support decisions for these populations.

Process of development

The Autism Guideline's first edition 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. Workstream 2 was led by the Ministry of Education and. Workstream 3 was funded by the Ministry of Health.

Stakeholder reference groups were set up to provide input to these workstreams from a wide range of providers and agencies. Māori input was 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.

Whilst separate methodologies were followed by the different contributors to the Guideline, broad evidence-based principles guided the development, including 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.

Each of the recommendations in this Guideline is followed by a 'strength of evidence ' grading used by the New Zealand Guidelines Group, designated by the letters 'A' (Good), 'B' (Fair), 'C' (Expert opinion), or 'I' (Insufficient) immediately after the recommendation. These 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.

Where a recommendation is based on the clinical and educational experiences of members of the guideline development teams, it is referred to as a Good Practice Point (GPP).

Living Guideline process

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

Every year since 2009, a topic within the Guideline has been prioritised for update by the LGG. 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 Living Guideline Group in revising relevant existing recommendations and good practice points in the Guideline, developing new ones, and grading these.

A comprehensive Supplementary Paper describing the systematic review and LGG decisions is prepared for each updated topic. These are published annually. 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. Future topic updates will continue to be made available via Whaikaha – Ministry of Disabled People’s website: https://www.whaikaha.govt.nz

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.

Revisions from the first seven Living Guideline updates[17-23] were incorporated into the second edition of the Guideline, and an additional six updates[24-29] into this third edition.

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, the new edition provides 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[30] [31] This perspective highlights the strengths of autism whilst acknowledging associated challenges.

A major focus of the revision has been changed terminology throughout to be more strength-based from a neurodiversity perspective. This was informed by a terminology guidance developed by autistic New Zealanders and led by autistic researcher Dr Ruth Monk.[32, 33] 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 de–pathologise 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'.

Consistent with Te Tiriti o Waitangi and Whāia Te Ao Mārama 2018–2022: The Māori Disability Action Plan,[14] 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).[34] Frameworks that reflect te ao Māori are described, including four dimensions of well-being (Whare Tapa Whā), and goals and principles to achieve excellent and equitable outcomes for Māori (Ka Hikitia's Outcome Framework). 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.[24] Enabling Good Lives principles have also been included.

In response to concerns raised since the publication of the Supplementary Paper on Applied Behaviour Analysis (ABA),[17] the LGG prepared an additional commentary for the third edition.

Finally, a significant new recommendation (Key Recommendation 7 in Part 4) 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.

Acknowledgements

This edition of the Autism Guideline and the entire Living Guideline process is proudly led by Whaikaha – Ministry of Disabled People in partnership with the Ministry of Education. Earlier editions of the Guideline were 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, the following individuals contributed significantly to the 3rd edition.

Autism/Takiwātanga Living Guideline Manager Marita Broadstock (INSIGHT Research) revised the 3rd edition and was the 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
- Emma Goodall, autistic author, artist, writer, speaker and researcher.

Revisions for the third edition were supported by the following members of the LGG (in alphabetical order):

- Tanya Breen, clinical psychologist
- Joanne Dacombe, child psychiatrist (LGG Co-Chair)
- Vijaya Dharan, educational psychologist, educator and academic
- Elizabeth Doell, speech and language therapist and academic
- Andrew Marshall, developmental paediatrician (LGG Co-Chair)
- Martyn Matthews, researcher
- Daniel Smith, autistic self-advocate
- Dorothy Taare-Smith, Takiwātanga education facilitator and whānau advocate
- Larah van der Meer, researcher

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

Helen Hayes worked tirelessly to bring this edition to publication, supported by her colleagues at Whaikaha. In particular we acknowledge Amanda Bleckmann and Matt Frost who have been firmly committed to the Living Guideline process since its inception in 2009.

Joanne Dacombe (Chair, ASAN AUNZ Board) provided Autistic peer review and proofing, offering helpful insights on many issues.

Finally, we acknowledge the invaluable contribution of autistic people//tāngata whaitakiwātanga who have driven this mahi. For sharing their experiences of being autistic as both participants in research and increasingly as co-researchers. And for being advocates for change in how autism is understood, described, researched, and embraced.

Executive summary

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

For each of these major areas, key recommendations have been identified for this Executive Summary.

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 autistic people, their 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 neurodevelopmental 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).

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.	✓

Key recommendations for diagnosis and initial assessment	Grade
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, whānau 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

Key recommendations for support for individuals, families, whānau and carers	Grade
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 support needs 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.

Educational programmes are based on a range of 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; and 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.

Transitions for learners on the autism spectrum need to be carefully planned to minimise stress. 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.

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

Key recommendations for education for learners on the autism spectrum	Grade
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 ritualistic/intensively focussed issues 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

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	✓

Key recommendations for mental health and wellbeing support	Grade
• **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)	
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
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 autism Guideline.	C

Key recommendations for mental health and wellbeing support	Grade
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 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 tertiary 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, 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
5. 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

Key recommendations for living in the community	Grade
6. 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
7. 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
8. Leisure and recreation planning should be included in a student/young person’s transition programme and this information shared with post-school providers.	C
9. 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
10. 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
11. 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
12. 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

Key recommendations for living in the community	Grade
13. 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
14. 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
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

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 & development	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. 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

Key recommendations for professional learning & development	Grade
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
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.	✓

Key recommendations for professional learning & development	Grade
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.	✓

Key recommendations for Māori perspectives	
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.	✓

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