

# **National Guideline**

# For the assessment and diagnosis of autism in Australia

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DRAFT UPDATED GUIDELINE FOR PUBLIC CONSULTATION

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## **Citing this Guideline**

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### Autistic people, families, and community

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## **Original Guideline Development Group**

We warmly acknowledge the efforts of the members of the Guideline Development Group that was responsible for developing the original Guideline in 2018, including the Research Executive Committee – Andrew Whitehouse, Kiah Evans, Valsamma Eapen, Margot Prior, and John Wray. We extend this acknowledgement to the many people who supported their work, and who are identified in the original Guideline document.

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# **Reference Group**

We warmly acknowledge and thank the members of the Reference Group, each of whom represented an organisation that is relevant to assessment and diagnosis of autism in Australia. The names of all members of the Reference Group, and the organisations they represent are included in the Guideline.

## **Further Assistance**

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# **Executive summary**

Autism affects the way a person understands and interacts with other people and the world around them. From a diagnostic perspective, the term Autism Spectrum Disorder (herein referred to as autism) is the collective diagnostic term for a group of neurodevelopmental conditions characterised primarily by differences in social-communication skills, and the presence of repetitive behaviours, intense or focussed interests and/or sensory differences (American Psychiatric Association, 2013). The behavioural features of autism are often present before 3 years of age but may not become apparent until the school years or later in life, as social and cognitive demands increase. Many autistic people experience co-occurring conditions such as language and learning difficulties, and a range of medical conditions. For many people, autism is much more than a diagnosis – it is central to their identity and sense of self.

This Guideline has been developed to support evidence-based, accurate, timely, and appropriate assessment and clinical diagnosis of autism in Australia. The Guideline focuses on practitioners who are involved in clinical assessment and diagnosis. It was first developed in 2018 by a Guideline Development Group and approved by the National Health and Medical Research Council. The current version is an update of the original Guideline and was conducted by a Guideline Development Group comprising 17 members including autistic people, family members, practitioners, researchers, and community members.

The Guideline presents 66 Consensus-Based Recommendations that span the assessment and diagnostic process that includes a process for making a referral, a Comprehensive Needs Assessment, a Diagnostic Evaluation when indicated, and referral for supports if a need is identified. Recommendations are key elements of practice that must be followed. They are accompanied by Good Practice Points that provide critical context for how each Recommendation should be implemented in clinical practice and applied with a specific population or in specific circumstances. A summary of evidence for each Recommendation is provided in the Supporting Evidence document. The methodology used to update the Guideline is presented in an Administration and Technical Report that accompanies the Guideline.

This updated Guideline continues to provide an evidence-based framework through which practitioners can work effectively, safely and appropriately in conducting assessments for autism in Australia. Professional associations and individual practitioners will benefit from, and are encouraged to continue to endorse, the Recommendations that reflect the best available evidence, modern ways of thinking and talking about evidence, and up to date views and perspectives from across the autistic and autism communities. It is recommended that the Guideline be further updated within 5 years.

# Plain language summary

This Guideline explains to practitioners involved in assessment and diagnosis of autism how to work in ways that are safe, timely, accurate, and helpful to individuals and their families.

This is a summary of the key messages.

#### **Section 1: Guiding principles**

Practitioners should work in partnership with the client to provide timely, accurate, and appropriate assessment, and where relevant, diagnosis. Practitioners should take a principled approach to providing services, including ensuring assessment is individualised, evidence-based, strengths-focused, culturally appropriate, and neurodiversity affirming.

#### Section 2: Foundations of assessment

Practitioners should be competent and provide high quality services that are safe and supportive. They should collect, use, and share information in ways that are helpful, respectful, and accessible. Client should be referred to supports when needed and desired at any point of the assessment and diagnostic process.

#### Section 3: Making a referral for assessment

Practitioners should discuss the possibility of referring a client for assessment and/or diagnosis of autism as soon as a need is identified. Practitioners should collect information that helps them to understand the client and their context, and whether a referral for assessment may be appropriate and desirable to them.

#### Section 4: Comprehensive Needs Assessment

Practitioners with specified qualifications and expertise should conduct an Assessment of Functioning and a Medical Evaluation when a diagnosis of autism is being considered. The Assessment of Functioning gives an understanding of the client's strengths and support needs in everyday activities. The Medical Evaluation gives an understanding of the individual's health and wellbeing. If the findings of the Comprehensive Needs Assessment suggest a possible diagnosis of autism, the diagnostic evaluation should be started.

#### Section 5: Diagnostic Evaluation

Practitioners with specified qualifications and expertise should conduct a Diagnostic Evaluation to determine whether a client meets criteria for a diagnosis of autism and/or other conditions. They should adopt a tiered approach to a diagnostic evaluation, commencing with a Lead Practitioner Diagnostic Evaluation, and if high diagnostic confidence cannot be reached, progressing to a Consensus Team Diagnostic Evaluation. Practitioners should consider a range of information and use their clinical judgement to reach a diagnostic decision. They should discuss the findings with the client and refer for further assessment and support if needed and desired.

# List of Recommendations

The following is a list of the Consensus-based Recommendations included in the Guideline. This list is provided as a quick reference guide only. It is critical that the Recommendations are read in the context of the accompanying Good Practice Points that are presented in the body of this Guideline.

All Recommendations are equally important and should be implemented. However, to help readers be aware of issues to consider when implementing the Recommendations (e.g., resources required, feasibility), each Recommendation includes a 'grade of Recommendation.' Where a Recommendation is 'conditional', it simply indicates that there are factors to consider during implementation.

This approach to providing grades is consistent with the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) Evidence to Decision framework (Alonso-Coello, Oxman et al., 2016; Alonso-Coello, Schünemann, et al., 2016). Further information about this approach is provided in the Administration and Technical Report.

# **Section 1: Guiding Principles**

# What guiding principles should be followed in the assessment and diagnosis of autism?

#### **Recommendation 1**

#### **Consensus-Based Recommendation**

**Client and family centred:** Practitioners should collaborate with individuals and their families with respect, and value and support their unique reasons for seeking assessment, their preferences, and contexts.

Grade of Recommendation: Strong

#### **Recommendation 2**

#### **Consensus-Based Recommendation**

**Strengths Focused:** Assessments and the sharing of findings should focus on the client's strengths, including skills, values, and interests that are personally meaningful to them and that promote their functioning, participation, and wellbeing.

► Grade of Recommendation: Strong

#### **Recommendation 3**

#### **Consensus-Based Recommendation**

**Holistic:** Assessment should be comprehensive and seek to understand all aspects of the client, including, their context, history, strengths and challenges, and aspirations - now and into the future - to the extent that is relevant to the purpose of the assessment for the client and that they are willing to share.

▶ Grade of Recommendation: Strong

#### **Recommendation 4**

#### **Consensus-Based Recommendation**

**Helpful:** Assessments should have an agreed purpose, aim to answer the questions the client has, help them identify and advocate for their strengths and support needs, and provide a pathway to supports where appropriate.

#### **Consensus-Based Recommendation**

**Evidence-Based:** Assessment and diagnostic practices should reflect the best available evidence from research, evidence from clinical practice and lived experience, and the client's preferences and priorities.

▶ Grade of Recommendation: Strong

#### **Recommendation 6**

#### **Consensus-Based Recommendation**

**Culturally Sensitive:** Practitioners should acknowledge and respect the values, knowledge, preferences, and cultural perspectives of the client; adopt culturally sensitive practices; and reflect on their own cultural knowledge and competency in their practice.

Grade of Recommendation: Strong

#### **Recommendation 7**

#### **Consensus-Based Recommendation**

**Respecting First Nations Peoples:** Services should be culturally safe for Aboriginal and Torres Strait Islander and other First Peoples, built on an acknowledgment of the barriers to accessing supports that they may experience; an understanding of current and historical truths and their enduring impact, and respect for deep connection to Country, language, customs, and traditions.

Grade of Recommendation: Strong

#### **Recommendation 8**

#### **Consensus-Based Recommendation**

**Neurodiversity-affirming:** Assessment and diagnosis should be neurodiversity-affirming, embracing each client's unique understanding of themselves, other people, and the world around them.

Grade of Recommendation: Strong

#### **Recommendation 9**

#### **Consensus-Based Recommendation**

**Competent:** Practitioners involved in assessment and diagnosis should have appropriate qualifications; up-to-date knowledge, skills, and attitudes gained through continuing professional development and supervision; experience; and regulation that is relevant to assessment and diagnosis of autism.

#### **Consensus-Based Recommendation**

Equity: All individuals should have access to timely and affordable assessment and diagnostic services regardless of their age, gender, cultural background, socioeconomic status, or geographical location.

▶ Grade of Recommendation: Strong

#### **Recommendation 11**

#### **Consensus-Based Recommendation**

Coordinated: Practitioners should work in a coordinated way with other service providers to improve access and reduce burden on the client.

## Section 2: Foundations of Assessment

# What should be the process for assessment and diagnosis of autism in the Australian context?

#### **Recommendation 12**

#### **Consensus-Based Recommendation**

The process for assessment and diagnosis of autism should include referral, a Comprehensive Needs Assessment that comprises an Assessment of Functioning and Medical Evaluation, and a Diagnostic Evaluation when appropriate, with referral for supports made at any stage a need is identified.

Grade of Recommendation: Strong

#### **Recommendation 13**

#### **Consensus-based Recommendation**

Practitioners should adopt a tiered approach to diagnostic evaluation, commencing with a Lead Practitioner Diagnostic Evaluation, and if high diagnostic confidence cannot be reached, progressing to a Consensus Team Diagnostic Evaluation.

Grade of Recommendation: Strong

# What knowledge, skills, training, supervision, and regulation are required to conduct components of the Comprehensive Needs Assessment and Diagnostic Evaluation?

#### **Recommendation 14**

#### **Consensus-Based Recommendation**

Practitioners should have knowledge of human development, diagnostic criteria for common neurodevelopmental and behavioural conditions (including autism), and appropriate support services.

Grade of Recommendation: Strong

#### **Recommendation 15**

#### **Consensus-Based Recommendation**

Practitioners should have the skills necessary to carry out their professional roles, as well as skills and experience specific to working with autistic clients.

#### **Consensus-Based Recommendation**

Practitioners should engage in continuing training and supervision necessary to carry out their professional roles when working with clients.

► Grade of Recommendation: Strong

#### What settings are appropriate for assessment?

#### **Recommendation 17**

#### **Consensus-Based Recommendation**

Assessment should occur in settings that are most appropriate for gathering an accurate and complete understanding of the client and their context, and that supports their privacy, safety, and comfort.

Grade of Recommendation: Strong

#### **Recommendation 18**

#### **Consensus-Based Recommendation**

Telehealth may be used to complement in-person meetings, but should not be used as the sole medium throughout the assessment and diagnostic process.

Grade of Recommendation: Strong

#### How should information be collected in an assessment?

#### **Recommendation 19**

#### **Consensus-Based Recommendation**

Practitioners should collect assessment information through talking to the client, and where relevant, the client's family and family-like people.

Grade of Recommendation: Strong

#### **Recommendation 20**

#### **Consensus-Based Recommendation**

Practitioners should collect assessment information by observing the way the client interacts with other people and the world around them in clinical and/or community settings.

#### **Consensus-Based Recommendation**

Practitioners should collect assessment information by consulting with all relevant stakeholders to collect information that relates to the referral and/or assessment.

• Grade of Recommendation: Strong

#### **Recommendation 22**

#### **Consensus-Based Recommendation**

Practitioners should consider using, but not rely solely on, standardised assessment, to support clinical decision making in relation to referral, Assessment of Functioning, Medical Evaluation, and Diagnostic Evaluation.

▶ Grade of Recommendation: Strong

#### How should information be shared?

#### **Recommendation 23**

#### **Consensus-Based Recommendation**

Practitioners should meet with the client and provide information that addresses their reason for accessing the assessment, including diagnostic outcome and to better understand their strengths, needs, and support options.

Grade of Recommendation: Strong

#### **Recommendation 24**

#### **Consensus-Based Recommendation**

Practitioners should document the assessment process and outcome, including their clinical judgements, recommendations, and support options.

Grade of Recommendation: Strong

#### **Recommendation 25**

#### **Consensus-Based Recommendation**

Practitioners should share information with the client in a way that is timely, accurate, accessible, and appropriate.

#### **Consensus-Based Recommendation**

Practitioners should share information with other practitioners in relation to referral, Assessment of Functioning, Medical Evaluation, and/or Diagnostic Evaluation; as well as to help inform the planning and delivery of supports.

► Grade of Recommendation: Strong

# When should referral for health, education, disability, social, and/or community supports be considered?

#### **Recommendation 27**

#### **Consensus-Based Recommendation**

Practitioners should refer the client to appropriate support as soon as a need is identified.

Grade of Recommendation: Strong

# How should the quality and safety of assessment and diagnostic services be optimised?

#### **Recommendation 28**

#### **Consensus-Based Recommendation**

Practitioners should ensure that the client is aware of their service and support options at each stage of the assessment and diagnostic process.

▶ Grade of Recommendation: Strong

#### **Recommendation 29**

#### **Consensus-Based Recommendation**

Practitioners should ensure that the client and/or their legal guardian provides consent for services received and referrals and can withdraw the consent at any time.

► Grade of Recommendation: Strong

#### **Recommendation 30**

#### **Consensus-Based Recommendation**

Practitioners should inform the client of any potential or actual conflicts of interest they may have in providing assessment services or making referrals.

#### **Consensus-Based Recommendation**

Practitioners should ensure that assessment services are delivered in safe environments.

Grade of Recommendation: Strong

#### **Recommendation 32**

#### **Consensus-Based Recommendation**

Practitioners should work in ways that support the client's emotional and mental health.

Grade of Recommendation: Strong

#### **Recommendation 33**

#### **Consensus-Based Recommendation**

Practitioners should inform the client about how they can provide feedback and make complaints about the services they receive.

Grade of Recommendation: Strong

#### **Recommendation 34**

#### **Consensus-Based Recommendation**

Practitioners should follow relevant international conventions, national and state/territory legislative requirements, and other associated principles, standards, and frameworks.

Grade of Recommendation: Strong

#### **Recommendation 35**

#### **Consensus-Based Recommendation**

Practitioners should be familiar with, and respect, the client's individual language and terminology preferences.

• Grade of Recommendation: Strong

#### **Recommendation 36**

#### **Consensus-Based Recommendation**

Practitioners should respect each for who they are; respect their goals, values, and preferences; and work in ways that promote and protect their human rights.

# Section 3: Making a Referral for Assessment

#### When should a referral for autism assessment be initiated?

#### **Recommendation 37**

#### **Consensus-Based Recommendation**

Practitioners should refer a client for a Comprehensive Needs Assessment and/or Diagnostic Evaluation, when a potential need is identified.

Grade of Recommendation: Strong

#### Who should initiate a referral for autism assessment?

#### **Recommendation 38**

#### **Consensus-Based Recommendation**

A referral for an assessment for autism should be initiated by a primary healthcare provider.

Grade of Recommendation: Strong

#### What information should be collected?

#### **Recommendation 39**

#### **Consensus-Based Recommendation**

Practitioners should collect information that helps them understand whether a referral for assessment that considers autism may be appropriate and desirable to the client.

Grade of Recommendation: Strong

#### What should be the outcome once a referral for assessment has been considered?

#### **Recommendation 40**

#### **Consensus-Based Recommendation**

Where a need for a diagnostic evaluation is established, the practitioner should make an appropriate referral.

#### **Consensus-Based Recommendation**

When a practitioner receives a referral, they (or their delegate) should explain the service they offer, indicative costs, book an appointment, and collect appropriate information.

## Section 4: Comprehensive Needs Assessment

#### When should an Assessment of Functioning be conducted?

#### **Recommendation 42**

#### **Consensus-Based Recommendation**

Practitioners should conduct an Assessment of Functioning when a diagnosis of autism is being considered.

Grade of Recommendation: Strong

#### **Recommendation 43**

#### **Consensus-Based Recommendation**

An Assessment of Functioning should be conducted, if relevant, at multiple points throughout the individual's life to ensure that changes to level of functioning and support needs are identified and acted on in a timely manner.

Grade of Recommendation: Strong

#### Who should conduct an Assessment of Functioning?

#### **Recommendation 44**

#### **Consensus-Based Recommendation**

An Assessment of Functioning should be conducted by medical, nurse, and/or allied health practitioners with specified qualifications, with input from all relevant stakeholders.

▶ Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

#### What information should be collected as part of an Assessment of Functioning?

#### **Recommendation 45**

#### **Consensus-Based Recommendation**

Practitioners should collect information in the Assessment of Functioning that helps them understand the client's characteristics, functioning, and their context, including their strengths and support needs, across life activities.

#### What should be the outcomes of an Assessment of Functioning?

#### **Recommendation 46**

#### **Consensus-Based Recommendation**

Where support needs have been identified, practitioners should inform the client of their support options and provide a referral if appropriate.

▶ Grade of Recommendation: Strong

#### **Recommendation 47**

#### **Consensus-Based Recommendation**

Where the findings of the Assessment of Functioning are consistent with a possible diagnosis of autism, the next step/s in the assessment and diagnostic process should be initiated.

► Grade of Recommendation: Strong

#### When should a Medical Evaluation be conducted?

#### **Recommendation 48**

#### **Consensus-Based Recommendation**

Practitioners should conduct a Medical Evaluation as part of a Comprehensive Needs Assessment.

Grade of Recommendation: Strong

#### Who should conduct a Medical Evaluation?

#### **Recommendation 49**

#### **Consensus-Based Recommendation**

Medical Evaluation and investigations relevant to neurodevelopmental and behavioural conditions should be conducted by a medical practitioner who holds general or relevant specialist registration with the Medical Board of Australia.

#### **Consensus-Based Recommendation**

A medical practitioner may receive assistance in collecting information for the Medical Evaluation from a nurse practitioner who holds general registration with the Nursing and Midwifery Board of Australia and is endorsed as a nurse practitioner or as a registered nurse with relevant experience as a clinical nurse specialist/consultant, practising under appropriate medical supervision.

• Grade of Recommendation: Strong

#### What information should be collected in a Medical Evaluation?

#### **Recommendation 51**

#### **Consensus-Based Recommendation**

Practitioners should gather information that helps them understand the client's health and wellbeing, including identifying needs, characteristics and findings that can inform differential diagnosis and recommendations for support options.

• Grade of Recommendation: Strong

#### What should be the outcomes of a Medical Evaluation?

#### **Recommendation 52**

#### **Consensus-Based Recommendation**

Where health and wellbeing needs have been identified, practitioners should inform the client of their options and provide a referral if appropriate.

Grade of Recommendation: Strong

#### **Recommendation 53**

#### **Consensus-Based Recommendation**

Where the findings of the Medical Evaluation are consistent with a possible diagnosis of autism, the next step in the assessment and diagnostic process should be initiated.

## Section 5: Diagnostic Evaluation

#### When should a Diagnostic Evaluation be conducted?

#### **Recommendation 54**

#### **Consensus-Based Recommendation**

A Diagnostic Evaluation should be conducted when there are indications of autism.

Grade of Recommendation: Strong

#### Who should conduct a Diagnostic Evaluation?

#### **Recommendation 55**

#### **Consensus-Based Recommendation**

The Diagnostic Evaluation should involve practitioners with specified medical and/or allied health qualifications, combined with advanced training and/or experience relevant to the differential diagnosis of autism from a range of neurodevelopmental and behavioural conditions.

Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

#### **Recommendation 56**

#### **Consensus-Based Recommendation**

When a Lead Practitioner Diagnostic Evaluation is conducted, it should involve input from at least one other medical and/or allied health practitioner with specified qualifications.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

#### **Recommendation 57**

#### **Consensus-Based Recommendation**

In circumstances where a Consensus Team Diagnostic Evaluation is warranted but the team is in a geographically distant location to the client's community, a partnership between the team and one or more community practitioners should be initiated.

#### What information should be collected in a Diagnostic Evaluation?

#### **Recommendation 58**

#### **Consensus-Based Recommendation**

Practitioners should collate information from all appropriate sources including the referral, Assessment of Functioning, and Medical Evaluation for consideration in the Diagnostic Evaluation.

▶ Grade of Recommendation: Strong

#### **Recommendation 59**

#### **Consensus-Based Recommendation**

Practitioners should gather and/or confirm information about social-communication and behavioural characteristics that are relevant to a diagnosis of autism, as well as characteristics that may inform differential diagnosis of other conditions.

• Grade of Recommendation: Strong

#### What information should be considered in making a diagnosis?

#### **Recommendation 60**

#### **Consensus-Based Recommendation**

Practitioners should take into account the client's characteristics and their impact on functioning individually and in comparison to people of the same chronological and developmental age when considering a diagnosis of autism.

Grade of Recommendation: Strong

#### **Recommendation 61**

#### **Consensus-Based Recommendation**

Practitioners should take into account potential gender-based differences in the characteristics of autism when considering a diagnosis of autism.

▶ Grade of Recommendation: Strong

#### **Recommendation 62**

#### **Consensus-Based Recommendation**

Practitioners should consider the potential impact of current and/or past psychosocial factors on the client's behavioural presentation and functioning, when considering a diagnosis of autism.

#### How should a diagnostic decision be made?

#### **Recommendation 63**

#### **Consensus-Based Recommendation**

Practitioners should use the current versions of either of the following international diagnostic manuals to make diagnostic decisions in relation to autism: the Diagnostic and Statistical Manual of Mental Disorders or the International Statistical Classification of Diseases and Related Health Problems.

Grade of Recommendation: Strong

#### **Recommendation 64**

#### **Consensus-Based Recommendation**

Practitioners involved in Diagnostic Evaluation should use their clinical judgement to reach their diagnostic decision by taking into account all relevant information from all stages of the assessment and diagnostic process.

Grade of Recommendation: Strong

#### What should be the outcomes of a Diagnostic Evaluation?

#### **Recommendation 65**

#### **Consensus-Based Recommendation**

Practitioners should discuss with the client and document the findings of the Diagnostic Evaluation, including whether a diagnosis of autism and/or other conditions is appropriate.

▶ Grade of Recommendation: Strong

#### **Recommendation 66**

#### **Consensus-Based Recommendation**

Practitioners should discuss and document recommendations, including referral for further assessment and/or supports, where appropriate.

# Introduction

Diagnosis is an important part of the clinical pathway for autistic individuals. A diagnosis can provide important information to facilitate self-understanding or understanding of another person, as well as information that can help determine the most appropriate supports for people to meet their goals. However, diagnosis of autism is not a straightforward clinical task, and requires specific knowledge, skills, and experience. Having an evidence-based Guideline that provides a consistent, high-quality clinical framework is critical to ensuring that practitioners can work effectively, safely and appropriately in conducting assessments for autism in Australia.

In 2018, the Autism CRC published Australia's first National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia. The Guideline combined systematic reviews of the research literature with extensive community consultation with Australian community. The Guideline was approved by the National Health and Medical Research Council (NHMRC), denoting that it was developed to the highest international standards. The Guideline is now widely adopted throughout Australia, additionally, it is underpinned by a variety of professional resources, for practitioners and the community. The success of the Guideline in improving the quality and consistency of practice in Australia is due to the individual efforts of practitioners, as well as endorsement and support from peak professional and community bodies that have provided expert insight and support for implementation activities. NHMRC approval requires that Guidelines are updated every five years.

# Update of the Guideline

This is the first update of this Guideline. In the past five years, there has been a significant change within the community in how autism is understood. For example, autism is no longer considered a disorder to be 'cured' but rather intrinsic to the individual, a neurodiversity, and for some people, their identity. The Guideline now uses identity-first language based on the preferences of the autistic and autism communities, while acknowledging that each person's individual preferences should be respected in clinical practice. In addition, evidence to inform clinical practice has also increased, such as in relation to telehealth delivery. Understanding and incorporating such changes helps to ensure the Guideline is up to date, evidence-based, relevant, and helpful to all those who use it and who are affected by its use.

There are, however, some challenges with assessment and diagnosis, that are largely unchanged. To illustrate, in completing the update, the Guideline Development Group received feedback from the autistic and autism communities that access to timely and affordable assessment and diagnosis services remains out of reach of many people. Evidence from this consultation, and research more broadly, consistently demonstrates that it is marginalised people who have the greatest access barriers, which includes Aboriginal and Torres Strait Islander Peoples, as well as people who are culturally and linguistically diverse, are socially disadvantaged, have complex health and communication needs, and/or live in rural and remote areas. This Guideline cannot address these systemic challenges to equitable service access, but it does specify what services should look like and how they should be delivered.

As with any Guideline update, the key question many will ask is 'what has changed?' The structure and format have changed, to (a) reflect implementation of the international standard for Guideline development (GRADE), (b) provide readers with a more concise set of Recommendations, and (c) adopt a similar structure across Autism CRC Guidelines to make them easier to read and follow. The overall number of Recommendations has reduced, even though new Recommendations (e.g., neurodiversity affirming practice) have been added. This has been possible through revising the Guideline questions and reducing repetition. Finally, some terminology has changed. For example, rather than refer to a 'Single Clinician Diagnostic Evaluation,' the Guideline refers to a 'Lead Practitioner Diagnostic Evaluation' to emphasise the practitioner leads the process but draws on information and evidence from all relevant sources including involvement of other practitioners.

The Guideline's purpose, scope, intended audience, and rigorous process through which it has been developed remain unchanged. In 2018, this was the first NHMRC-approved National Guideline relating to autism in Australia, and it presented Recommendations reflecting multiple converging sources of evidence from research, clinical practice, and the views and preferences of the autistic and autism communities. The 2023 Guideline update combines new evidence and perspectives with those from the original, resulting in revised Recommendations where required.

## **Purpose and objectives**

This Guideline was developed to support clinicians involved in clinical assessment that may result in a diagnosis of autism spectrum disorder (ASD) according to the Diagnostic and Statistical Manual of Mental Disorders which is currently in its 5th edition (DSM-5-TR; American Psychiatric Association, 2022) and the World Health Organization's International Statistical Classification of Diseases and Related Health Problems, which is currently in its 11th edition (ICD-11; World Health Organization, 2019). The specific objectives were to develop a Guideline that:

- 1. Describes a rigorous framework for accurately determining whether an individual meets the criteria for a clinical diagnosis of autism.
- 2. Outlines a comprehensive approach to identify related support needs.
- 3. Contains sufficient flexibility to apply to the assessment of a child, adolescent or adult of any age, gender, cultural or language background, communication or intellectual capacity, and medical complexity, living anywhere in Australia.
- 4. Describes a feasible process for clinical service providers to administer across the full breadth of community settings in Australia, including public and private healthcare settings.
- 5. Meets the needs and expectations of individuals being assessed and their caregivers.

### Scope

The Guideline is focused on assessment that is conducted where a clinical diagnosis of autism is being considered. The process includes making a referral, Assessment of Functioning, Medical Evaluation, and Diagnostic Evaluation. The scope of the Guideline update – which is unchanged from the original Guideline - was determined prior to the commencement of the research and community consultation activities, and is summarised in Table 1.

Aspect	In Scope	Out of Scope
Recipients of services	Children, young people, and adults of all ages, for whom a clinical diagnosis of autism may be relevant.	Children, young people, and adults not meeting this criterion.
Focus of assessment	Assessment where a diagnosis of autism is being considered. This includes assessment of individual characteristics, strengths, and supports needs, whether or not the assessment leads to a diagnostic evaluation and decision.	Assessment where a diagnosis of autism is not being considered, or that focuses solely on goal setting and/or support planning.
Outcomes of assessment	Sharing and documentation of findings, as well as recommendations for supports where relevant.	The provision of supports following assessment and diagnosis, irrespective of whether a diagnosis of autism was given.

#### Table 1. The scope of the Guideline.

In presenting the scope, two considerations are highlighted:

- People access medical and allied health assessments for a variety of reasons. For example, a person may seek an assessment if they have a difference or delay in development, are experiencing restrictions and/or barriers in life activities, and/or may have a diagnosable condition. A person may also access an assessment to better understand their experience of the world, but not be seeking a clinical diagnosis. In each case, the practitioner would work within their scope of practice to meet the client's needs. The Guideline focuses specifically on clinical diagnosis of autism, rather than attempt to account for all possible reasons for assessment or to provide Recommendations for all aspects of practice.
- 2. It is critical that an assessment for autism takes place in the context of a broader neurodevelopmental and behavioural assessment. This Guideline is intended to operate within the assessment processes applicable to working with children, adolescents, and adults presenting with characteristics of a broad range of neurodevelopmental conditions.

### **Target users**

The primary target users of this Guideline are Australian practitioners who conduct assessments that may result in a clinical diagnosis of autism.

Secondary target users of this Guideline include the following groups:

- 1. Individuals who have characteristics that may be explained by autism diagnosis, as well as others (e.g., partners, family) who can use this Guideline to understand how to initiate, and what to expect from, assessment for autism.
- 2. Australian medical, nursing, allied health, and education professionals and organisations who work with children, young people, and/or adults who show characteristics of autism can use the Guideline to know when and how to make a referral for autism assessment.
- Australian medical, nursing, allied health, and education professionals and organisations who work with autistic people can use this Guideline to understand what assessments should involve to ensure recommendations are implemented and avoid duplication of services.
- 4. Australian training providers, including peak bodies and tertiary institutions, can use this Guideline to tailor educational and clinical resources, courses, and qualifications to ensure participants achieve the learning outcomes required to contribute to assessment for autism, where doing so will be within their scope of practice and consistent with Guideline Recommendations.
- 5. Australian funding bodies can use this Guideline to align resource allocation with the recommended process for assessment and diagnosis of autism.

### **Diagnostic Criteria for autism**

There are two sets of diagnostic criteria commonly used throughout Australia and the world. The American Psychiatric Association publishes the Diagnostic and Statistical Manual of Mental Disorders which is currently in its 5<sup>th</sup> edition (DSM-5-TR; American Psychiatric Association, 2022). The World Health Organization publishes the International Classification of Diseases, which is currently in its 11<sup>th</sup> edition (ICD-11; World Health Organization, 2019).

# **Guideline development process**

The Guideline was developed in 2018 and updated in 2023 according to the approach described in the *Guidelines for Guidelines* handbook (2016), published by the National Health and Medical Research Council (NHMRC). In 2023, The Grading of Recommendations, Assessment, Development and Evaluation (GRADE) method was used to move from questions, to evidence, and then revised recommendations (Schünemann, 2013).

## Step 1: Establishing the Guideline Development Group

The first step was to establish a Guideline Development Group (GDG) to lead the research and community consultation process. To commence this process, the Co-chairs identified a range of perspectives that were critical to updating the Guideline. These perspectives included lived expertise (autistic people, family members), clinical expertise (medical and allied health practitioners), expertise in human ethics, and the lived expertise of one or more Aboriginal and/or Torres Strait Islander person/s. The Co-chairs also identified research expertise that would be relevant, including in relation to co-design of the GDG processes and research activities, that included systematic reviews, community consultation, and Guideline development. Finally, the Co-chairs considered the need for continuity from the 2018 release of the Guideline through the update, to ensure the accurate interpretation of the original context, questions, evidence, and Recommendations. Following this, the Cochairs identified people who had knowledge, skills, and experience relevant to each of these required perspectives, and distributed invitations via email. Consideration was given to ensuring diversity within the GDG.

The GDG members are listed in Table 2. Among the 17-member group were autistic adults; parents and other family members of autistic children, including individuals with complex support needs; an Aboriginal person; a person with expertise in ethics and research integrity; practitioners with experience across government and non-government sectors; and researchers with expertise in the guideline development process, including community consultation. Three members of the GDG for this Guideline update were also part of the team that led the development of the Guideline in 2018 (Andrew Whitehouse, Kiah Evans, Valsamma Eapen). Half of the GDG members involved in the update brought both professional and personal expertise relating to autism to the GDG, which was also diverse with respect to age, gender, and culture. Processes were put in place to declare and manage any potential conflicts of interest, consistent with the NHMRC and GRADE methodologies.

Name	Position, role, and expertise
Mr Gary Allen	Gary Allen is the Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. Gary has worked in the human research ethics area since 1997, working with a number of research institutions, state and federal departments, private companies and research ethics committees internationally. He also has a degree in education and a professional doctorate in social sciences. Gary brings extensive experience in regards to the national and international governance of ethical conduct in research.
Dr James Best	Dr James Best is a General Practitioner and Chair of the Child and Young Person's Health, Faculty of Special Interests Group, within the Royal Australian College of General Practitioners. He brings experience working with children and families in the areas of behaviour, parenting and autism, and is extensively published in medical and mainstream publications on these and other child health topics.
Dr Nicole Dargue	Dr Nicole Dargue is a Lecturer within the Autism Centre of Excellence, School of Education and Professional Studies at Griffith University. Her research interests include factors impacting learning and communication in autistic individuals, with a focus on nonverbal communication including gestures. She is an accredited Clinical Neuropsychologist who brings experience working with autistic individuals of all ages when navigating the diagnostic process.
Prof Valsamma Eapen	Professor Valsamma Eapen is the Chair of Infant, Child and Adolescent Psychiatry at the University of New South Wales. An internationally- recognised child psychiatrist and researcher, Valsamma's expertise combines extensive experience in childhood mental health and developmental disorders from a clinical and basic science research perspective.
Dr Kiah Evans	Dr Kiah Evans coordinated the development of the first Guideline from 2016 to 2018. She has held leadership roles in multiple research projects over the past six years that have focussed on exploring the perspectives of autistic adults, caregivers, clinicians and other key stakeholders in relation to assessment of functioning and diagnostic processes related to autism and other neurodevelopmental conditions. This included a large program of research to investigate the psychometric properties of existing assessment of functioning measures and supervision of doctoral research projects to develop new measures based on the ICF. Kiah co-led community consultation to evaluate the comparable guideline in New Zealand and was an international consultant for the development of a comparable guideline in Vietnam. She has qualifications and teaching experience in the field of health professions education.

Dr Emma Goodall (Co-chair)	Dr Emma Goodall is an autistic author, advocate, qualified meditation and mindfulness teacher, and adjunct research fellow at the University of Southern Queensland. She is the Manager for Content & Research for Positive Partnerships, Senior Industry Fellow at Griffith University, and also runs Healthy Possibilities, a consultancy offering personal life coaching alongside autism-specific continuing professional development for educators and families and National Disability Insurance Scheme (NDIS) services (many with a link to interoception). Emma speaks widely on the topic of interoception and the role mindful body awareness plays in emotional regulation. Dr Emma Goodall was Co-chair of the Guideline Development Group for this Guideline.
Ms Emma Hinze	Emma Hinze is a PhD candidate within the School of Applied Psychology at Griffith University. She brings lived experience as a parent and caregiver to her autistic son, as well as knowledge gained through her research and work with autistic adolescents and adults.
Mr Will Foster	Will Foster is an autistic adult who enjoys spending time with family and friends, building various Lego projects, engaging in the community, and enjoys making puppets, cooking, and exercising.
Dr Mandira Hiremath	Dr Mandira Hiremath is a general paediatrician at Western Health, is a board director for the Neurodevelopmental and Behavioural Paediatric Society of Australasia and has also completed further studies in public health. She has extensive clinical experience in the diagnosis of autism spectrum disorder in children and additionally supporting children and their families through a range of mental health and developmental concerns.
Dr Wenn Lawson	Dr Wenn Lawson is an Adjunct Associate Professor at Curtin University, WA. Wenn is a Senior Researcher in the area of autism and supports PhD students through supervision, working on various projects, and is a member of the Curtin Autism Research Group (CARG).
Dr Rhylee Sulek	Dr Rhylee Sulek is a Research Fellow within the School of Health Sciences and Social Work, Griffith University. She brings experience in working with young autistic children and their families when receiving early supports and therapies, and the inclusion of key stakeholders in the co-production of research.
Dr Samarra Toby	Dr Samarra Toby is a First Nations Medical Doctor who specialises in General Practice. Dr Toby has an interest in nutritional and environmental medicine, aerospace medicine, medical ecology and First Nations Translational Health Research.

A/Prof David Trembath (Co-chair)	David Trembath is an Associate Professor in Speech Pathology at the Menzies Health Institute Queensland, Griffith University and Honorary Research Fellow at CliniKids, Telethon Kids Institute. He brings over 20 years of clinical-research experience working with autistic children and their families. David was Co-chair of the Guideline Development Group responsible for developing the Autism CRC's National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia. David was the Co-chair of the Guideline Development Group for this Guideline update.
Dr Kandice Varcin	Dr Kandice Varcin is a Research Fellow at the Menzies Health Institute Queensland, Griffith University and Honorary Research Associate at CliniKids, Telethon Kids Institute. She is also a registered psychologist who brings experience and expertise in research focused on autism, early development and the evaluation of therapies and supports for young children and their families.
Dr Hannah Waddington	Dr Hannah Waddington is a Senior Lecturer at Victoria University of Wellington and the Clinic Lead of the Victoria University of Wellington Autism clinic. She is also a practicing educational psychologist who brings experience in provision of early support to autistic children and their families.
Prof Andrew Whitehouse (Co-chair)	Andrew Whitehouse is a Speech Pathologist and Angela Wright Bennett Professor of Autism at the Telethon Kids Institute and the University of Western Australia. Andrew is also the Director of CliniKids, a clinical research centre of excellence for autistic children, and is the Autism CRC's Research Strategy Director. He brings over 20 years' clinical research experience in working with autistic children and their families. He also brings experience in Guideline development, having chaired the development of the original version of the National Guideline for the Assessment and Diagnosis of Autism in Australia, and co-chaired the development of the National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia.
Dr Rachelle Wicks	Dr Rachelle Wicks is an autistic research fellow within Griffith University's Autism Centre of Excellence. She brings lived experience as a late- diagnosed woman and professional experience in early literacy and assessment for young autistic children, as well as knowledge of the varied perspectives and needs of individuals within the autistic and autism communities gained through her research and work with autistic children, their families, and service providers.

To support its work in community consultation, the GDG formed a Reference Group, comprising representatives from organisations with members that play a critical role in assessment and diagnosis of autism or support and reflect the views of autistic people and family members; that represent Aboriginal and Torres Strait Islander Peoples, and represent Culturally and Linguistically Diverse communities; or that were from a relevant Government Department (Department of Social Services, Department of Health) or agency (National Disability Insurance Agency). Members of the Reference Group, and the national peak bodies they represented, are listed in Table 3.

Stakeholder group	Organisation	Representative	Position
Autistic people	Autistic Self Advocacy Network – Australia and New Zealand	Cheryl Koch	Board member
Family members of autistic people	Autism Awareness Australia	Nicole Hurley	Head of fundraising and partnerships
First Nations peoples	National Aboriginal Community Controlled Health Organisation (NACCHO)	Jess Styles	Director, Programs
Culturally and linguistically diverse communities	Australian Multicultural Health Collaborative	Daniel Coase	Senior Advisor
Focusing on health	Neurodevelopmental and Behavioural Paediatrics Society of Australasia	John Wray	Member
Focusing on health	Royal Australian College of General Practitioners	Alison Palmer	Member
Focusing on health	Royal Australian and New Zealand Colleague of Psychiatrists	Matthew Sellen	Member, RANZCP Section of Psychiatry of Intellectual and Developmental Disabilities

#### **Table 3.** Members of the Reference Group.

Focusing on social- communication functioning	Speech Pathology Australia	Amy Fitzpatrick	Senior Advisor - Disability	
Focusing on physical functioning	Australian Physiotherapy Association	Kristy Nicola	APA Paediatric National Group – Deputy Chair	
Focusing on cognitive functioning and mental health	Australian Psychological Society	Catriona Davis- McCabe	APS President	
Focusing on sensory functioning and occupations	Occupational Therapy Australia	Gaynor Gray	Divisional Manager (QLD) Occupational Therapy Australia	
Focusing on rural health	National Rural Health Alliance	Susanne Tegen	Chief Executive	
Representing service providers (peak body)	Australian Autism Alliance	Frances Scodellaro	Member	
Representing researchers	Australasian Society for Autism Research	Josephine Barbaro	Treasurer	
Government	Australian Government Department of Education	Susan Aitkin	Improving Student Outcomes Division	
Government	Department of Social Services	Angela Warner	Assistant Director, Autism Policy Team, Disability Support Branch	
Government	National Disability Insurance Agency	Sam Bennett	General Manager Policy, Advice and Research	

## **Step 2: Revising the Guideline questions**

The GDG reviewed questions that formed the basis of the original version of the Guideline and considered whether any changes were required. In considering possible changes, the GDG reflected on (a) whether the questions remained relevant, (b) if any new questions should be added to reflect changes in the community and practice, and (c) if re-wording and/or organisation of questions could improve readability and reduce repetition within the Guideline. The revised questions are presented in Table 4.

The GRADE framework typically recommends the formulation of questions structured in a PICO format (Patient, Intervention, Comparison, Outcome). However, because of the purpose and objectives of the current Guideline, the relevance of PICO questions to the aspects of practice considered, and the nature and availability of research evidence that would inform the answers to the questions, the questions for this Guideline were structured around aspects of professional practice that impact on the experiences and outcomes for individuals accessing an assessment for autism. For this same reason, the Recommendations included in the Guideline are considered Consensus-Based Recommendations, drawing on evidence from the research literature, combined with evidence collected through extensive community consultation.

**Table 4.** Questions that provided the foundation for the research activities andcommunity consultation underpinning the Guideline.

Section	Question			
Guiding principles	What guiding principles should be followed in the assessment and diagnosis of autism?			
Foundations of assessment	What should be the process for assessment and diagnosis of autism in the Australian context?			
	What knowledge, skills, training, support, and regulations are required to conduct components of the Comprehensive Needs Assessment and Diagnostic Evaluation?			
	What settings are appropriate for assessment?			
	How should information be collected in an assessment?			
	How should information be shared?			
	When should referral for health, education, disability, social, and/or community supports be considered?			
	How should the quality and safety of the assessment and diagnostic process be optimised?			
Making a referral for	When should a referral for autism assessment be initiated?			
assessment	Who should initiate a referral for autism assessment?			
	What information should be collected?			
	What should be the outcome once a referral for assessment has been considered?			
Comprehensive	When should an Assessment of Functioning be conducted?			
Needs Assessment	Who should conduct an Assessment of Functioning?			
	What information should be collected as part of an Assessment of Functioning?			
	What should be the outcomes of an Assessment of Functioning?			
	When should a Medical Evaluation be conducted?			
	Who should conduct a Medical Evaluation?			
	What information should be collected in a Medical Evaluation?			
	What should be the outcomes of a Medical Evaluation?			
Diagnostic Evaluation	When should a Diagnostic Evaluation be conducted?			
	Who should conduct a Diagnostic Evaluation?			
	What information should be collected in a Diagnostic Evaluation?			
	What information should be considered in making a diagnosis?			
	How should a diagnostic decision be made?			
	What should be the outcomes of a Diagnostic Evaluation?			

## Step 3: Gathering evidence

Evidence can take many forms. For this Guideline, there was a concerted effort to gather evidence through systematic reviews of the research evidence alongside extensive community consultation. Evidence was gathered from October to December 2022 using a structured research process. Ethical approval for the community consultation activities was procured through the Griffith University Human Research Ethics Committee (2022/780). The day-to-day work in gathering evidence was primarily undertaken by 9 members of the GDG: Nicole Dargue, Emma Goodall, Emma Hinze, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse, and Rachelle Wicks with research assistant support from Briohny Dempsey, Amy Giesberts, and Libby Groves. The literature reviews and community consultation activities are described in detail in the Administration and Technical Report. In brief, these activities comprised the following:

#### Literature review

An umbrella review was conducted to collect and synthesise research evidence, published between 2018-2022, that relates to assessment and diagnosis of autism. This was a systematic review of 16 systematic reviews that examined evidence relating to: (a) existing guidance for assessment and diagnosis, (b) clinical tools and processes, (c) considerations regarding personal and environmental factors, and (d) experiences of members of the autistic and autism communities.

#### **Community consultation activities**

Two community consultation activities were conducted to provide opportunities for community members in Australia to give input into the update of the Guideline. The community consultation activities were advertised through the Autism CRC mailing list and traditional and social media networks:

- An online survey designed to understand experiences and current views and preferences of the autistic and autism communities regarding assessment and diagnosis of autism in Australia. The survey was open to all members of the autistic and autism communities. It was accessed 1,000 times with 805 people providing informed consent and responses.
- 2. A series of nine focus groups designed to provide an opportunity for autistic adults, family members, and practitioners to reflect on and discuss their experiences, views and preferences regarding assessment and diagnosis of autism in Australia. There were 246 people who registered to attend a focus group, with 68 participating.

## Step 4: Reformatting the Guideline Text

The original Guideline was developed according to NHMRC *Guidelines for Guidelines* handbook (2016) but did not use the GRADE method for moving from evidence to Recommendations. To ensure that GRADE could be applied when updating the Guideline, reconfiguration of Recommendations and accompanying text was required, prior to updating Recommendations based on new evidence and applying GRADE. The process of reconfiguring the text also provided an opportunity to align formatting with the approach taken with Autism CRC's *National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia* (Trembath et al., 2023). Aligning the formatting in this way should help practitioners in moving seamlessly from one Guideline to the other when working with autistic children and will lay the foundation for similar consistency across other Guidelines in the future.

The process of reconfiguring the Recommendations and accompanying text involved five steps:

- 1. All text from the original Guideline was transferred to a Microsoft Excel spreadsheet and organised according to the original Guideline questions.
- 2. This text was re-organised according to the updated Guideline questions.
- 3. The Recommendations and accompanying text related to each of the updated Guideline questions was reviewed, individually and as a group.
- 4. The text was reconfigured into a set of revised Recommendations, Good Practice Points, and if relevant accompanying text. At this point, no changes in the scope or meaning of the Recommendations was allowed, only changes to the way the information was presented.
- 5. The Chair of the original Guideline Development Group (Andrew Whitehouse) reviewed the original and reconfigured text to ensure continuity in scope and meaning of Recommendations between the original Guideline and updated draft Recommendations, Good Practice Points, and accompanying text.

## Step 5: Moving from evidence to Recommendations

An iterative process, built around an Evidence to Decision framework, was used to move from evidence to Recommendations (Alonso-Coello, Oxman et al., 2016; Alonso-Coello, Schünemann, et al., 2016). The process was led within the GDG by a Draft Recommendations Working Group (DRWG; Nicole Dargue, Emma Goodall, Emma Hinze, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse, Rachelle Wicks) with support from research staff (Veronica Frewer, Libby Groves) to analyse data from the community consultation activities and review the draft updated Recommendations in light of the evidence generated.

#### Evidence review and preparation of draft 1 of updated Recommendations

Members of DRWG and research staff reviewed the draft updated Recommendations against evidence from the umbrella review and community consultation activities. In doing so, they considered if each Recommendation should be retained in its original form, be revised based on new evidence, or be removed based on new evidence. The team also considered whether one or more new Recommendations should be added. Proposed edits, along with the supporting evidence from the umbrella review and/or community consultation were documented first in an excel spreadsheet that contained the evidence summary for each Recommendation, and second in the Draft Updated Guideline. One Cochair reviewed the proposed edits and either endorsed them immediately or sought further clarification and consensus with the team before endorsing. The second Co-chair and all members of the DRWG reviewed the edits and any disagreements were discussed until consensus was achieved.

#### Guideline Development Group review of Draft 1 of updated Recommendations

The DRWG shared the draft updated Recommendations and Good Practice Points with the GDG. The GDG provided feedback at the monthly meeting and via suggestions in shared documents.

# Grade of Recommendation judgements and preparation of Draft 2 of updated Recommendations

Members of the DRWG incorporated feedback provided by GDG members to further update Recommendations and Good Practice Points. The DRWG also independently completed a review and judgement of each Recommendation against the seven criteria required within the GRADE Evidence to Decision framework (Alonso-Coello, Oxman et al., 2016; Alonso-Coello, Schünemann, et al., 2016). The judgements related to certainty of evidence, benefits and risks, values and preferences, resource implications, equity considerations, acceptability, and feasibility. The judgements occurred over five rounds, with the first involving independent review, followed by consensus review, and then review by the broader GDG. Based on the judgements, each Recommendation was then classified as either a 'strong' Recommendation or a 'conditional' Recommendation, as per the GRADE process and reflecting the confidence in the clarity of the balance between desirable and undesirable consequences. In the case of this Guideline, 'conditional' Recommendations indicated: uncertainty around alignment with values and preferences of autistic people; a possible reduction in health equity across populations; uncertainty around the acceptability of the Recommendation for practitioners; and/or a possible lack of feasibility in implementation. The classifications reflect the judgements of the GDG, based on the available evidence and other relevant considerations such as alignment with international conventions. The complete set of judgements is provided in the Supporting Evidence document accompanying this Guideline.

The grade of a given Recommendation does not reflect whether that Recommendation should be implemented or prioritised. All Recommendations within the Guideline represent good practice and should be implemented. Rather, the grade of Recommendations (strong, conditional) is intended to support users in considering a range of factors when implementing a given Recommendation, such as the benefits and harms, resources needed, and the acceptability to individuals, families, and practitioners. A grading of a Recommendation as 'conditional' reflects a judgment that there are key factors to consider during implementation. Further information on the grading of each Recommendation is provided in the Supporting Evidence document.

The DRWG prepared the Draft updated Guideline and shared it with the GDG, alongside the complete set of evidence summaries and Evidence to Decision (EtD) judgements. These documents were reviewed and then discussed by members at a meeting of the GDG. The GDG endorsed the documents, subject to further minor edits and formatting.

## Step 6: Public consultation on Draft updated Guideline

The GDG prepared the Draft updated Guideline and supporting documents (Summary of Evidence, Administration and Technical Report, and Easy Read summary) for public consultation.

#### Ahead of public consultation

The public consultation on the Draft updated Guideline complied with Section 74A of the Commonwealth National Health and Medical Research Council Act 1992 and accompanying regulations. The following activities were undertaken ahead of the public consultation period:

- Autism CRC updated its webpage devoted to the Guideline development to reflect the upcoming consultation period and the invitation to participate.
- Autism CRC announced the upcoming public consultation period, via email distributed to people who had registered specifically for updates on the Guideline, as well as people who were on the Autism CRC communications database more broadly. Key professional and consumer organisations were identified through the Reference Group and were invited to provide feedback. Further announcements were made via Autism CRC social media, and then re-posted by GDG members.
- A Co-chair of the GDG emailed the Office of the Director General, Chief Executive or Secretary of each state, territory, and Commonwealth Health Department to prepare those offices for the publication of the Draft updated Guideline.

# Involvement of Aboriginal and Torres Strait Islander Peoples and culturally and linguistically diverse communities

For a Guideline to serve the needs of all Australians, it is critical that the guideline development process includes proper consideration of issues relating to Aboriginal and Torres Strait Islander Peoples and culturally and linguistically diverse communities. These considerations include recognising the enduring impact of historical injustices, discrimination, and marginalisation of Aboriginal and Torres Strait Islander Peoples; the importance of understanding and embracing culturally-bound understandings of family practices and disability; and the need to ensure that every Australian has access to culturally-responsive and appropriate health and education services, delivered by people with appropriate knowledge, skills, understanding, and experience. The GDG took the following steps to ensure the Guideline Recommendations were responsive to these and other considerations relevant to these peoples and communities. First, the Guideline Development Group included Aboriginal representation. Second, the Reference Group included representatives from the peak organisation serving the health of Aboriginal and Torres Strait Islander Peoples: The National Aboriginal Community Controlled Health Organisation (NACCHO).

# **Reading the Guideline**

In preparing the updated Guideline, the GDG adopted several key approaches to writing about autism and presenting Recommendations that (a) reflect contemporary understanding of autism and language preferences within the autistic and autism communities, and (b) reduce the need for repetition and elaboration within and across Recommendations and Good Practice Points.

## Talking about autism

The term 'autism spectrum disorder (ASD)' is used only when directly referring to DSM-5-TR (DSM-5-TR; American Psychiatric Association, 2022) or ICD-11 (World Health Organization, 2019) diagnostic criteria. Elsewhere, the Guideline refers to autism. Identity-first language (i.e., autistic) is used when referring to individuals with an autism diagnosis or those who self-identify and/or are engaged or seeking to engage in the assessment and diagnostic process. The Guideline acknowledges and respects the different preferences held by members of the autism and autistic communities [e.g., 'with autism/ASD', 'on the (autism) spectrum'].

## **Talking about practitioners**

The term 'practitioner' is used to refer to medical, nursing, and allied health practitioners who are identified in the Guideline as having a direct role in assessment for autism. It is acknowledged that the term 'clinician' is also commonly used in practice and can be considered synonymous with 'practitioner' when reading the Guideline.

## Talking about individuals, families, and other people

The term 'client' is used to refer to the individual accessing assessment and/or diagnostic services and any family and family-like people who are directly involved in supporting them. Some individuals will participate in the process independently, whereas others will have other people involved out of personal choice and/or due to factors such as their age or communication/cognitive abilities (e.g., partners, family and family-like people, friends). The Guideline recognises that families come in many forms, and a family unit may include one or more parents, caregivers, partners, siblings, and/or biologically related and unrelated children and adults. The Guideline recognises that conceptions of parents and families are culturally bound and equally valid. In presenting Recommendations and Good Practice Points, only the 'client' is referred to for brevity, consistency, and to avoid assumptions regarding the nature of support an individual may seek, need, and/or desire. The exception is where taking this approach would lead to ambiguity about the role of the family and/or significant others. The term 'client' should be read in the holistic sense, to include the individual and other people who are relevant.

## Talking about neurodiversity-affirming practice

A neurodiversity perspective acknowledges that people experience and interact with the world in different ways. Inherent in this view is that there is no one 'normal' way of thinking,

learning, and behaving, and therefore differences in behaviours should not be seen as 'deficits.' In the context of autism, a neurodiversity perspective views brain-based and behavioural differences observed in autistic people as reflecting natural human variation. Neurodiversity-affirming practices seek to affirm each neurodivergent person's identity. In the context of assessment for autism, this term refers to conducting an assessment, sharing findings, and providing recommendations for support that value and respect each person's unique understanding of other people and the world around them, rather than viewing autism as a disorder or condition that should be 'cured.'

## Assent, consent, and involvement in decision-making

It is implicit that client consent will be obtained and respected in implementing all Recommendations and Good Practice Points. Ensuring that clients, and where appropriate, family and support people due to the client's age and/or capacity to provide informed consent, can make informed decisions about themselves and the assessment and diagnostic services they access is a core element of ethical practice. Therefore, each Recommendation and Good Practice Point must be considered, and implemented, in ways that respect each person's preferences and have their consent. For example, Recommendations and Good Practice Points that refer to collecting and sharing information with other practitioners would only be implemented with informed consent, and in ways that are tailored to the client's preferences.

Consistent with a human rights framework, the Guideline recommends that autistic people, including children and young people, are involved in decisions regarding the services they access and any supports they are referred to. How this occurs will vary between people and take into consideration factors such as how old they are, their cognitive and communication skills, and the nature of the decision being made. Practitioners are expected to draw on their clinical training, adhere to the ethical and professional practice requirements of their professional organisations, and abide by the laws and regulations governing their practice in upholding their professional obligations and duty of care to individuals and their families.

When the client is a child, young person, or a person of any age with reduced capacity to provide consent, seeking the individual's assent, and obtaining a parent or legal guardian's consent, are critical and complementary processes that help ensure the individual's rights are protected. This protection extends to circumstances in which the individual is unable to comprehend the decision being made due to their age, cognitive skills, and/or communication needs. In circumstances where the client cannot not reasonably be expected to take on the full burden of decision making, parents and legal guardians fulfil an essential role in weighing up the potential benefits and risks of a particular course of action to act in the individual's best interests.

When working with children, there may be circumstances in which the preferences of a child and parent or legal guardian are in conflict. Such conflicts should be resolved through a principled approach, given that the issues to consider will be unique to the particular circumstance. A key consideration is the balancing of principles honouring, respecting, and supporting the autonomy and self-determination of the child, while also maintaining duty of care. The child's right to have their views sought, heard, and respected is enshrined in laws and conventions in Australia and internationally. Accordingly, the child's views should be

prioritised, provided doing so maintains the practitioner's duty of care within the ethical, professional, legal, and regulatory context in which they are operating.

The Guideline is purposefully non-prescriptive in relation to addressing who should be involved in seeking assent, when the client is a child, young person, or a person of any age with reduced capacity to provide consent. Nor is the Guideline prescriptive in relation to when assent should be sought (e.g., how often), how much information should be provided to the individual, what type of information should be provided, and how practitioners should respond when clear assent is not forthcoming or withdrawn. Again, a principled approach is required, within the ethical, professional, legal, and regulatory context in which the practitioner is operating. Of particular consideration here is the understanding that all individuals have capacity to assent and that they may communicate their wishes using a range of communication modes. The modes a client may use to express assent, or lack thereof, include but are not limited to movements, physical actions, facial expressions, expression of emotions, gestures, manual signs, vocalisations, words, drawing, writing, and use of augmentative and alternative communication modes.

Clients may also express their assent, or lack thereof, by acting on the environment in ways that convey their assent, or lack thereof, such as actively retrieving preferred materials to indicate willingness to participate in an assessment activity; or rejecting, hiding, or destroying objects and materials to express a lack of assent. Furthermore, clients may communicate in idiosyncratic ways (i.e., unique to them) or indicate their feelings about a particular interaction, activity, or environment through fluctuations and changes in their interest, engagement, or need for other interests and activities (e.g., an increase in sensory behaviours in response to increasing anxiety).

Practitioners should assume that assent may not be given and that even when provided, it may change or be withdrawn. For example, an assessment activity that a client is comfortable doing on one day (e.g., a child completing a play-based assessment in a clinic) may be distressing on another, due to their fluctuating sensory or other needs. Practitioners should continually ask themselves: "What evidence do I have that the client is assenting to the service I am providing?" Where the evidence for a clear answer to this question is lacking, changing, or ambiguous, practitioners should respond by ceasing or adjusting the activity, at the same time consulting the client, to the extent possible, and parents or guardians regarding appropriate next steps, at all times maintaining their duty of care.

## **Recommendations and Good Practice Points**

The Guideline is structured into a set of 66 Consensus-Based Recommendations with associated Good Practice Points:

- **Consensus-Based Recommendations** are key elements of practice that must be followed for a practitioner to deliver evidence-based supports.
- Good Practice Points are linked to specific Recommendations and are elements of practice that provide critical context to that Recommendation, such as how a Recommendation should be operationalised in clinical practice, or how it is applied to a specific population or under specific circumstances.

The Recommendations and Good Practice Points may include examples for illustrative purposes. These examples are provided to further contextualise the information and should not be interpreted as a complete list.

# Making use of the Guideline and all supporting documents

To make the best use of the Guideline, it is essential that practitioners familiarise themselves with its entire content by reading all sections. The Recommendations relate to the entire assessment and diagnostic process, so it is strongly advised that the Recommendations are taken as a whole, rather than in isolation.

# **Updating the Guideline**

Guidelines should be regularly updated to incorporate new research and clinical evidence, as well as the changing understandings and preferences of the autistic and autism communities. The next update of the Guideline should take place within five years.

# Acknowledging and respecting Aboriginal and Torres Strait Islander Peoples

The Guideline Development Group offers respect to the Traditional Owners and Custodians across the country now known as Australia. We acknowledge the journey of Elders past, and we recognise historical truths and the enduring impact for First Nations Australians. We recognise and value the knowledge and wisdom of Elders present, as well as those emerging leaders who share a continuing connection with Aboriginal and Torres Strait Islander Peoples and Country. We are strengthened together through upholding the continuation of the First Peoples lore of cultural and spiritual ways that help to grow individuals and families strong.

We recognise inequalities and commit our efforts to work alongside Aboriginal and Torres Strait Islander Peoples to better understand their lived experience. We support engaging two-worlds to progress deep knowledge of culturally safe, responsive, and timely supports and services.

The Guideline Development Group have strengthened existing relationships and initiated new networks to support *proper way* collaboration and consultation. Our intention is to continue the journey of walking alongside First Nations Peoples through deep listening and upholding shared knowledge. We acknowledge the valuable contribution of Aboriginal and Torres Strait Islander Peoples to this Guideline and recognise the perspectives, preferences, and priorities of First Peoples as key to guiding good practice across Australia. Guiding principles provide a framework through which practitioners can make decisions in relation to all aspects of the assessment and diagnostic process for autism. The list of principles reflects good practice more generally and is not intended to be exhaustive. Instead, the principles presented are those that were emphasised in the original Guideline, updated research review, and community consultation as being crucial to working in ways that are safe, appropriate, and desirable to clients in relation to assessment and diagnosis. These principles may also be helpful to autistic individuals, family members, supporters, and other interested stakeholders within the autistic and autism communities in making decisions about assessment and diagnostic services.

# What guiding principles should be followed in the assessment and diagnosis of autism?

Practitioners should work in ways that place the client at the centre of all decision-making. Assessment and (where appropriate) diagnosis, should be strengths focused, holistic, and helpful to the client. The approaches, decisions, and recommendations made must be ethical and evidence based. Practitioners should have knowledge and skills, and work in ways, that are culturally safe and respectful of Aboriginal and Torres Strait Islander Peoples and other First Peoples within Australia. They should work and communicate in ways that are neurodiversity-affirming and thus value each person for who they are. Practitioners should contribute to the provision of timely and accessible assessment and diagnostic services, that are coordinated for the benefit of clients.

#### **Recommendation 1**

#### **Consensus-Based Recommendation**

**Client and family centred:** Practitioners should collaborate with individuals and their families with respect, and value and support their unique reasons for seeking assessment, their preferences, and contexts.

► Grade of Recommendation: Strong

#### **Recommendation 2**

#### **Consensus-Based Recommendation**

**Strengths Focused:** Assessments and the sharing of findings should focus on the client's strengths, including skills, values, and interests that are personally meaningful to them and that promote their functioning, participation, and wellbeing.

#### **Consensus-Based Recommendation**

**Holistic:** Assessment should be comprehensive and seek to understand all aspects of the client, including, their context, history, strengths and challenges, and aspirations - now and into the future - to the extent that is relevant to the purpose of the assessment for the client and that they are willing to share.

▶ Grade of Recommendation: Strong

#### **Recommendation 4**

#### **Consensus-Based Recommendation**

**Helpful:** Assessments should have an agreed purpose, aim to answer the questions the client has, help them identify and advocate for their strengths and support needs, and provide a pathway to supports where appropriate.

▶ Grade of Recommendation: Strong

#### **Recommendation 5**

#### **Consensus-Based Recommendation**

**Evidence-Based:** Assessment and diagnostic practices should reflect the best available evidence from research, evidence from clinical practice and lived experience, and the client's preferences and priorities.

▶ Grade of Recommendation: Strong

#### **Recommendation 6**

#### **Consensus-Based Recommendation**

**Culturally Sensitive:** Practitioners should acknowledge and respect the values, knowledge, preferences, and cultural perspectives of the client; adopt culturally sensitive practices; and reflect on their own cultural knowledge and competency in their practice.

#### **Consensus-Based Recommendation**

**Respecting First Nations Peoples:** Services should be culturally safe for Aboriginal and Torres Strait Islander and other First Peoples, built on an acknowledgment of the barriers to accessing supports that they may experience; an understanding of current and historical truths and their enduring impact, and respect for deep connection to Country, language, customs, and traditions.

• Grade of Recommendation: Strong

#### **Recommendation 8**

#### **Consensus-Based Recommendation**

**Neurodiversity-affirming:** Assessment and diagnosis should be neurodiversity-affirming, embracing each client's unique understanding of themselves, other people, and the world around them.

Grade of Recommendation: Strong

#### **Recommendation 9**

#### **Consensus-Based Recommendation**

**Competent:** Practitioners involved in assessment and diagnosis should have appropriate qualifications; up-to-date knowledge, skills, and attitudes gained through continuing professional development and supervision; experience; and regulation that is relevant to assessment and diagnosis of autism.

▶ Grade of Recommendation: Strong

#### **Recommendation 10**

#### **Consensus-Based Recommendation**

**Equity:** All individuals should have access to timely and affordable assessment and diagnostic services regardless of their age, gender, cultural background, socioeconomic status, or geographical location.

#### **Consensus-Based Recommendation**

**Coordinated:** Practitioners should work in a coordinated way with other service providers to improve access and reduce burden on the client.

## **Section 2: Foundations of Assessment**

While assessment and diagnostic services should be individualised and will vary based on factors such as geographical location, resources, and community needs and preferences, they should have five foundational characteristics:

- 1. Assessment and diagnostic services in Australia should be offered in ways that contribute to ensuring a clear and consistent process for all clients seeking assessment, and where appropriate, diagnosis.
- 2. Services should be delivered by people with appropriate knowledge, skills, attitudes, training, supervision, and regulation.
- 3. Services should be offered in settings that are appropriate and accessible for the client.
- 4. At each stage of the assessment process, clients should be provided with information that is helpful, respectful, and accessible; and be referred to supports when needed.
- 5. Services delivered should be high quality with appropriate safeguards in place.

### The purpose of an assessment

In its most literal form, the ultimate purpose of an assessment that considers a possible diagnosis of autism is to determine if they meet the diagnostic criteria for autism, and/or other conditions. However, it is essential that assessments achieve a much broader aim of understanding the client and their context. There are countless aspects to consider, and different people conceptualise and prioritise these in different ways. Common aspects that are referred to in research and clinical practice include understanding the client's goals, aspirations, characteristics, activities, functioning, strengths, existing supports, support needs, contextual barriers and facilitators; to name just a few.

To ensure accuracy, transparency, and consistency in this Guideline, the focus of assessment is conceptualised and talked about in relation to a biopsychosocial model – the International Classification of Functioning, Disability, and Health (ICF: World Health Organisation, 2001) - that considers an individual's (a) body functions and structures, (b) activities, (c) participation in life situations, and (d) their context which includes environmental and personal factors. These factors are summarised in Recommendations for brevity as the client's *characteristics, functioning,* and *context*, including *strengths and support needs*. Other aspects are, at times, referred to in Recommendations and Good Practice Points where there explicit mentioning is relevant.

# What should be the process for assessment and diagnosis of autism in the Australian context?

Everyone should have access to a high quality, evidence-based process for assessment for autism. The process must be sufficiently structured to ensure all relevant aspects are included, while sufficiently flexible to cater for the needs, preferences, and circumstances of each client and the context in which services are provided. The assessment and diagnostic process presented below in Figure 2.1, reflects the findings of the original Guideline and systematic review of research evidence and community consultation conducted to update the Guideline. This process commences with a referral and concludes with the sharing of the assessment findings with the client. Referral for supports occurs whenever a need is identified.

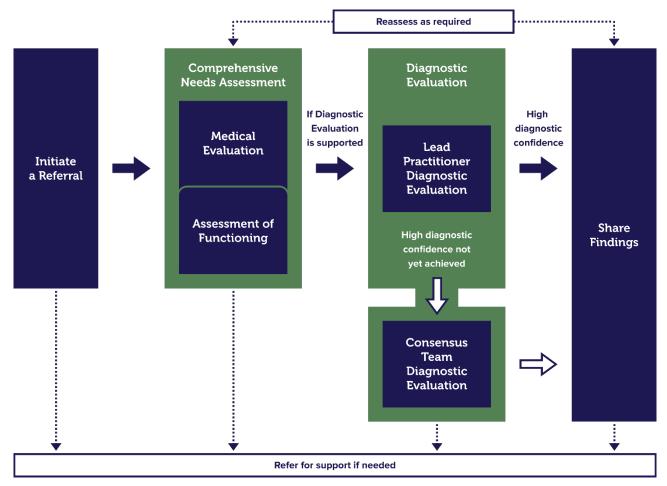


Figure 2.1. Process for assessment and diagnosis of autism in Australia.

#### Making a referral

The process begins with a referral for assessment for autism. This referral will typically come from a General Practitioner or Aboriginal and Torres Strait Islander Health Practitioner (note that Aboriginal and Torres Strait Islander Liaison Officers, Health Workers, and Health Workers with Isolated Practice Authorisation can also refer). However, another health professional who is already working with the client may also make a referral.

#### **Comprehensive needs assessment**

The Comprehensive Needs Assessment is a core component of all assessments for autism and seeks to understand all relevant aspects of the client's characteristics, functioning, context, strengths, and support needs. This includes consideration of the opportunities and experiences that have advantaged or disadvantaged the client and influenced their functioning and development prior to the assessment. The Comprehensive Needs Assessment consists of an Assessment of Functioning and a Medical Evaluation:

- Assessment of Functioning: The Assessment of Functioning focusses on understanding the client's characteristics, functioning, context, strengths and support needs. The assessment includes taking a case history and typically involves the use of a variety of tools such as interview, observations, and assessment tools designed to examine functioning in a range of relevant ICF domains (World Health Organisation, 2013). The Assessment of Functioning contributes to identifying characteristics that may be relevant to a diagnosis of autism and/or other conditions.
- **Medical Evaluation:** The Medical Evaluation focuses on the client's health, functioning, and wellbeing, and typically includes taking a case history, physical examination, and further clinical assessments where indicated. The Medical Evaluation contributes to identifying characteristics that may be relevant to a diagnosis of autism and/or other conditions.

In most cases it is suggested that the Comprehensive Needs Assessment is conducted initially so that the information collected may be utilised to (a) refer the client to appropriate supports at the earliest opportunity, (b) help determine if a Diagnostic Evaluation is required, and (c) assist the practitioner/s conducting the Diagnostic Evaluation.

#### **Diagnostic evaluation**

The Diagnostic Evaluation seeks to investigate whether a client meets diagnostic criteria for a clinical diagnosis of autism and/or other conditions. The Guideline recommends that the practitioner/s use the current versions of either of the following international diagnostic manuals to make diagnostic decisions in relation to ASD: the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR; American Psychiatric Association, 2022) or the International Statistical Classification of Diseases and Related Health Problems (ICD-11; World Health Organization, 2019).

If the client does not meet criteria for a clinical diagnosis of autism, other possibilities are explored that may explain their profile of characteristics, strengths, and support needs. To ensure that the Diagnostic Evaluation is both accurate and efficient in evaluating for the range of autism presentations, the Guideline incorporates a degree of flexibility that enables the process to be tailored based on the complexity of the client's individual clinical presentation.

#### A tiered approach

The Guideline recommends a tiered approach to diagnostic evaluation that seeks to improve access and reduce burden on clients:

- A Lead Practitioner Diagnostic Evaluation involves a practitioner with specified medical or allied health qualifications considering all of the available information and making a diagnostic decision. Although this practitioner leads the process, it is recommended that at least one other relevant practitioner should be consulted.
- A **Consensus Team Diagnostic Evaluation** involves multiple practitioners with specified qualifications, tailored to the specified assessment needs, contributing to a diagnostic decision based on consensus.

As illustrated in Figure 2.1, the Guideline recommends that a Lead Practitioner Diagnostic Evaluation be used when there is sufficient evidence on which a diagnosis of autism and/or other conditions can be confirmed or ruled out with high confidence. A Consensus Team Diagnostic Evaluation is recommended when a client presents with a high level of ambiguity and/or complexity from the outset (e.g., subtle characteristics, indications that multiple diagnoses may be relevant) or a Lead Practitioner Diagnostic Evaluation is inconclusive. Each option involves drawing on information from multiple practitioners with appropriate qualifications, knowledge, skills, training, supervision, and regulation, along with insights from other relevant stakeholders. The assessment and diagnostic process is intended to be flexible and can be adapted based on the unique circumstances of the client and the decision-making of the Assessment Team.

#### **The Assessment Team**

Accurate, evidence-based, assessment and diagnosis of autism requires the involvement of practitioners with qualifications, knowledge, skills, training, supervision, and regulation that facilitates the collection and synthesis of information in an appropriate and ethical manner, followed by clinical reasoning, to (a) understand the client, their functioning, context, and support needs and (b) consider the relevance of a range of health conditions including autism with reference to diagnostic criteria (DSM-5-TR, American Psychiatric Association, 2022; ICD-11, World Health Organisation, 2019). These practitioners have specified medical, nursing, and/or allied health qualifications relevant to the differential diagnosis of autism.

Table 2.1 presents a recommended list of qualifications that practitioners should have to be eligible to conduct elements of the assessment and diagnostic process. Appendix 2.1 presents an overview of the knowledge, skills, training, and regulation of practitioners commonly involved in the Assessment Team. Appendix 2.2 presents examples of how the Assessment Team may work together in different ways within the assessment and diagnostic process.

Table 2.1. Recommended professional disciplines eligible to conduct components of the assessment and diagnostic process for autism.

Profession	Comprehensive Needs Assessment		Diagnostic Evaluation	
	Assessment of Functioning	Medical Evaluation	Lead Practitioner	Consensus Team
Medical practitioner	$\checkmark$	$\checkmark$	Specified <sup>b</sup>	Specified <sup>b</sup>
Psychologist	$\checkmark$	×	Specified <sup>c</sup>	$\checkmark$
Nurse	Specified <sup>a</sup>	Specified <sup>a</sup> (assist)	×	×
Occupational therapist	$\checkmark$	×	×	$\checkmark$
Social worker	$\checkmark$	×	×	×
Speech pathologist	$\checkmark$	×	×	$\checkmark$

× indicates those profession are not recommended to conduct that component of the assessment.

<sup>a</sup> For a nurse conducting a Comprehensive Needs Assessment, it is recommended that they be a nurse practitioner (with appropriate credentials in neurodevelopmental disorder assessment) or a clinical nurse specialist/consultant (practicing under appropriate medical supervision).

<sup>b</sup> To conduct a Diagnostic Evaluation, medical practitioners are recommended to have a specialist registration in the field of community child health, general paediatrics, psychiatry or neurology, or have general registration with at least six years of relevant experience in the assessment and diagnosis of neurodevelopmental conditions.

<sup>c</sup> To conduct a *Lead Practitioner Diagnostic Evaluation*, psychologists are recommended to have a practice of endorsement in clinical psychology, educational/developmental psychology, or neuropsychology.

The Assessment Team is responsible for coordinating and conducting the various elements of the assessment process, but they can be supported by a range of other stakeholders. For example, the Assessment Team will liaise with other medical, nursing, allied health, disability and/or educational professionals to obtain further information about the client being assessed, to support the Comprehensive Needs Assessment and Diagnostic Evaluation. These other professionals are not part of the Assessment Team; however, their input may be helpful to obtain a more complete clinical picture of the client's presentation in their everyday contexts and/or provide specialist guidance to explore alternative explanations for presenting characteristics. These professionals typically require registration with a professional board and/or accreditation from the peak organisational body specific to their discipline. Appendix 2.3 presents a list of examples of professions that may contribute information that is relevant to the assessment and diagnostic process.

#### **Recommendation 12**

#### **Consensus-Based Recommendation**

The process for assessment and diagnosis of autism should include referral, a Comprehensive Needs Assessment that comprises an Assessment of Functioning and Medical Evaluation, and a Diagnostic Evaluation when appropriate, with referral for supports made at any stage a need is idetified.

Grade of Recommendation: Strong

#### **Good Practice Points:**

- 12.1 A referral should be made when a client presents with characteristics that indicate possible relevance of a diagnosis of autism.
- 12.2 A Comprehensive Needs Assessment should be conducted to understand all relevant aspects of the client, their functioning, context, strengths, and support needs, including an Assessment of Functioning and a Medical Evaluation.
- 12.3 A Diagnostic Evaluation should be conducted when a possible diagnosis of autism is indicated.
- 12.4 At each stage of the process, findings should be shared with the client in ways that are accurate, sensitive, and helpful.
- 12.5 At each stage, a referral should be made if support needs are identified.

#### **Recommendation 13**

#### **Consensus-based Recommendation**

Practitioners should adopt a tiered approach to diagnostic evaluation, commencing with a Lead Practitioner Diagnostic Evaluation, and if high diagnostic confidence cannot be reached, progressing to a Consensus Team Diagnostic Evaluation.

• Grade of Recommendation: Strong

#### **Good Practice Points:**

13.1 Common reasons for not being able to achieve high diagnostic confidence include clients presenting with subtle characteristics of autism, or with characteristics that may be relevant to one or more other conditions.

## What knowledge, skills, training, supervision, and regulation are required to conduct components of the Comprehensive Needs Assessment and Diagnostic Evaluation?

#### **Recommendation 14**

#### **Consensus-Based Recommendation**

Practitioners should have knowledge of human development, diagnostic criteria for common neurodevelopmental and behavioural conditions (including autism), and appropriate support services.

► Grade of Recommendation: Strong

- 14.1 Practitioner's knowledge should be aligned with the nature of their role and responsibilities in the assessment and diagnostic process.
- 14.2 Practitioner's knowledge should extend beyond autism, to include a range of other relevant conditions. Where broader knowledge is lacking, other practitioners with this knowledge should also be involved, if appropriate.
- 14.3 Practitioner's knowledge should include understanding and/or awareness of:
  - Culturally safe practices when working with Aboriginal and Torres Strait Islander Peoples and other culturally diverse groups within the community.
  - Typical human development across the age range of clients they see in their practice.
  - Possible causes and characteristics of a range of relevant conditions, including early characteristics and progression of these conditions.
  - Socio-economic, geographical, cultural, psychosocial (including trauma), and contextual factors that may affect the presentation of the client's condition/s impact on their functioning.
  - Health, education, social, community, and disability supports that are available in the local area, including referral pathways and access to interpreters.
- 14.4 Practitioner's knowledge of autism should include understanding/awareness of:
  - The range of ways autism may influence functioning and support needs.
  - Characteristics of autism, across the lifespan, including early signs.
  - Characteristics of autism in females, males, nonbinary, and gender-diverse clients.

- The dynamic nature of support needs that may be experienced by clients resulting from fluctuations in contextual factors (e.g., sensory characteristics, situational demands).
- The range of community views regarding language and terminology preferences and neurodiversity-affirming practice.
- Services and supports that are tailored for autistic people, including those offered by autistic people and practitioners.
- 14.5 Where a practitioner is involved in a Diagnostic Evaluation of autism, they must also have knowledge of:
  - Diagnostic criteria for autism and common co-occurring conditions.
  - Diagnostic tools used to assess for autism and common co-occurring conditions, to inform differential diagnosis.
  - The role, scope of practice, and potential contributions of all other relevant medical and allied health practitioners who can inform the Diagnostic Evaluation.

#### **Consensus-Based Recommendation**

Practitioners should have the skills necessary to carry out their professional roles, as well as skills and experience specific to working with autistic clients.

• Grade of Recommendation: Strong

- 15.1 Practitioner's skills should align with the nature of their role and responsibilities in the assessment and diagnostic process.
- 15.2 Practitioners should have a general set of skills that are consistent with their professional responsibilities, scope of practice, and regulation requirements, including effective communication, use of assessment tools, clinical decision-making, and report writing.
- 15.3 Practitioners working with clients for whom a diagnosis of autism may be appropriate, should have additional skills in:
  - Communicating with individuals with intellectual disability and/or complex communication needs, including clients who communicate mainly or only in ways other than speech (e.g., augmentative and alternative communication; AAC).
  - Creating accessible clinical environments, such as avoiding potential sources of sensory discomfort when choosing lighting, furnishings, and materials.
  - Communicating the benefits and risks of potential supports and making referrals.

- 15.4 Where a practitioner is involved in a Diagnostic Evaluation of autism, they must also have skills in:
  - Differential diagnosis of autism and common co-occurring conditions.
  - Evaluating characteristics of autism, including in the use of diagnostic tools where appropriate.
  - Collaborating with other practitioners in gathering information to inform a differential diagnosis.
  - Communicating diagnostic decisions to clients in a clear and helpful manner.
- 15.5 Practitioners should have the communication skills necessary to engage with clients in a way that:
  - Builds rapport and trust.
  - Fosters a collaborative client-practitioner relationship.
  - Ensures a two-way exchange of information in a way that is accurate, meaningful, and clear.
  - Demonstrates that the information the client shares is listened to and valued.
  - Is non-judgmental and conveys empathy.
  - Appropriately manages expectations and concerns.

#### **Consensus-Based Recommendation**

Practitioners should engage in continuing training and supervision necessary to carry out their professional roles when working with clients.

• Grade of Recommendation: Strong

- 16.1 Practitioners should engage in continuing professional development to maintain currency of, and further develop, their knowledge, skills, and attitudes.
- 16.2 Practitioner's training and supervision should align with the nature of their role and responsibilities in the assessment and diagnostic process.
- 16.3 Early career practitioners should have opportunities to develop knowledge and skills, and gain experience, specific to working with autistic clients under the supervision of practitioners who are competent in the assessment and diagnostic process.

- 16.4 All practitioners should have training and support that reflects their professional responsibilities, scope of practice, and regulation requirements, including training in relation to:
  - Culturally safe practices, including when working with Aboriginal and Torres Strait Islander Peoples.
  - The impact of characteristics of common neurological and behavioural conditions on functioning and participation in life situations.
  - Evaluating each client's individual characteristics, context, strengths, support needs, and preferences.
  - Where appropriate, administration of standardised and non-standardised assessments, including the specified prerequisite qualification level for administering standardised measures in clinical practice.
  - Clinical reasoning in weighing evidence, integrating findings, and reaching assessment conclusions.
  - Communicating effectively with clients and other professionals.
- 16.5 Practitioner's working with clients for whom a diagnosis of autism may be relevant, should have additional training to administer appropriate autism-specific screening, assessment, and/or diagnostic tools.
- 16.6 Where a practitioner is involved a Diagnostic Evaluation of autism, they must also have training in:
  - Differential diagnosis of autism and common co-occurring conditions.
  - Evaluating characteristics of autism, including the use of diagnostic tools where appropriate.
- 16.7 Practitioners should engage in continuing professional development in a range of areas relevant to assessment, including maintaining relevant knowledge, training and expertise through peer observation and peer mentoring.
- 16.8 Practitioners should access clinical supervision that is commensurate with their knowledge, skills, and professional experience.
  - Practitioners should receive clinical supervision to facilitate reflection on their own learning needs and wellbeing, and to encourage continuing professional development in a systematic and planned manner.
  - Practitioners should receive clinical supervision and mentoring at a frequency and in a mode (e.g., individual versus group, in-person versus tele supervision) that aligns with their professional experience working with autistic clients.
  - Practitioners should put in place ways to regularly monitor their own wellbeing and have access to supports should that be necessary, to ensure they are fit to practice.

## What settings are appropriate for assessment?

A range of settings can be appropriate within the assessment and diagnostic process, and the decision as to which setting/s are relevant should be made in consultation with the client. In selecting settings, consideration should be given to the client's comfort, convenience, and privacy, as well as practical considerations such as location, suitability of spaces (e.g., ambient noise, client safety, and distractions), and time for travel and attending appointments. The setting/s chosen must be helpful in terms of gathering relevant information, including the opportunity to observe relevant behavioural characteristics and learn from the client's sharing of experiences.

#### **Clinic settings**

A clinic setting refers to a medical or allied health practice that a client attends specifically for assessment purposes. A clinic setting comprises all spaces within the practice, such as waiting, interview and/or clinical rooms.

Advantages of a clinic setting include the opportunity to:

- Standardise the physical, sensory, and social environment.
- Observe the client in new environments, where their usual strategies and supports may be less effective, provided doing so is not intended to cause embarrassment, distress, or harm.
- Ensure the client's privacy.
- Arrange the environment so that conversations about the client can occur privately out of respect for the client's emotional wellbeing (e.g., parents not being asked to talk about their child's difficulties with their child in close proximity).
- Support collaboration between different practitioners working in the same setting.
- Reduce costs and wait times by co-locating practitioners and minimising practitioner travel.

#### **Community settings**

A community setting refers to familiar contexts where the client goes about one or more of their life activities or situations. The potential advantages of collecting information in community settings include the opportunity to:

- Observe the client in familiar contexts where they are more likely to feel more confident, in control, and less anxious.
- Observe the interaction of the client with other people and their environment, including the barriers and facilitators of their functioning.
- Minimise time burden on the client.

#### **Telehealth settings**

The process for assessment and diagnosis should involve in-person assessment, where possible, and always for the Medical Evaluation given the need for physical examination. However, telehealth consultation can be used to support in-person assessment where doing so will maintain or improve diagnostic accuracy (e.g., by seeing the client in everyday environments) and equity of access (e.g., for clients who are geographically distant from

assessment services). When deciding whether assessments are conducted in-person or via telehealth, practitioners should consult with clients and consider their comfort, convenience, and privacy, as well as practical considerations such as location, suitability of spaces (e.g., ambient noise, client and occupational safety, distractions), and in the case of telehealth, access to appropriate and reliable equipment and connectivity. Evidence for the accuracy, feasibility, and acceptability of telehealth in assessment and diagnosis of autism is emerging, including for contexts in which it is less, more, or equally effective than in-person consultation, and practitioners should make decisions about its use within an evidence-based practice decision-making framework.

#### **Recommendation 17**

#### **Consensus-Based Recommendation**

Assessment should occur in settings that are most appropriate for gathering an accurate and complete understanding of the client and their context, and that supports their privacy, safety, and comfort.

Grade of Recommendation: Strong

- 17.1 The practitioner should work with the client to determine the most appropriate setting/s for assessment.
- 17.2 Assessment may occur in clinical and/or community settings.
- 17.3 The setting/s should be places:
  - The client feels comfortable and confident to discuss their reasons for seeking assessment and share information about themselves and their context.
  - That are private, including when conducting a Medical Evaluation.
  - In which the practitioner/s can make direct observations of behaviour relevant to Assessment of Functioning, Medical Evaluation, and/or Diagnostic Evaluation.
- 17.4 The setting/s should enable the practitioner to gather information about the client's characteristics, functioning context, and support needs in the context of life activities, such as at home, school, post-school education and vocational settings, and in the community more broadly.
- 17.5 Practitioners should collect information about the client's functioning in all appropriate community settings. Gathering information in relation to community settings may occur through a combination of directed observation as well as learning from information shared by the client, and other people when appropriate.

#### **Consensus-Based Recommendation**

Telehealth may be used to complement in-person meetings, but should not be used as the sole medium throughout the assessment and diagnostic process.

► Grade of Recommendation: Strong

#### **Good Practice Points**

- 18.1 Where possible, practitioners should provide the client with the opportunity for inperson assessment.
- 18.2 It is important that at least one in-person assessment session is conducted as part of the assessment and diagnostic process.
- 18.3 The Medical Evaluation should be conducted in-person, given the need for physical examination.
- 18.4 If telehealth is used as the predominant medium for conducting part of an autism assessment and/or sharing the findings, it is recommended that a local practitioner (or other professional with relevant expertise) be physically present with the client during the telehealth meetings.
- 18.5 Practitioners should be aware of emerging evidence to suggest that:
  - Telehealth can be an effective, feasible, and acceptable way of conducting aspects of an Assessment of Functioning and Diagnostic Evaluation.
  - There can be benefits to telehealth over in-person consultation, including in relation to cost, time, and accessibility.
  - There can be barriers to telehealth, including having access to appropriate equipment and internet connectivity, challenges observing behaviours and understanding contexts, privacy, and rapport building (for some clients).
  - Clients will differ in terms of their preferences for in-person versus telehealth delivery.

# How should information be collected in an assessment?

At each stage of the assessment and diagnostic process, it is crucial that practitioners collect information relevant to the purpose of the assessment. The type of information that should be collected is addressed in subsequent Guideline (Assessment of Functioning, Medical Evaluation, Diagnostic Evaluation). However, there are commonalities in terms of 'how' the information should be collected, such as by talking with clients, observing and learning about them in a range of contexts, and learning from the observations and reports of other people and practitioners. The process for collecting information must ensure that the client's developmental and medical history is taken into account and may also include

collection at multiple timepoints. Special consideration should be given when using assessment tools, including standardised tests, to ensure they are appropriate for the client and the findings are interpreted and used correctly.

#### **Recommendation 19**

#### **Consensus-Based Recommendation**

Practitioners should collect assessment information through talking to the client, and where relevant, the client's family and family-like people.

• Grade of Recommendation: Strong

- 19.1 Practitioners should talk with the client, to the extent possible, to collect information relevant to the aims of the assessment, taking into consideration their age, cognitive abilities, and communication skills.
- 19.2 Where appropriate, practitioners may talk with family and family-like people, to collect information. In having these discussions (e.g., talking to a parent in relation to a child), practitioners should consider how they talk about the individual being assessed (e.g., sensitive in discussing challenges and support needs) and whether doing so is best done with the individual being assessed present or absent.
- 19.3 Practitioners should be aware that asking the client, and where relevant family members and supporters, to repeat information that they have provided previously, either to the same practitioner or another, can be burdensome, disrespectful and/or distressing, and thus avoid the need to do so where possible through reviewing available documentation and liaising with other professionals.
- 19.4 Given autism is heritable, practitioners should consider that family members (e.g., parents) involved in the assessment may be autistic themselves, and have preferences for how information is requested and shared (e.g., asking and answering questions)
- 19.5 Practitioners should show sensitivity and clinical insight when asking questions to gather information.
- 19.6 Practitioners should be aware that the way a question is asked can affect a client's response:
  - Open-ended questions may be helpful in enabling the client to speak openly on topics of their choosing but may also be ambiguous and/or challenging for some clients.
  - Closed questions may be helpful in eliciting specific information, but practitioners should be aware that they may limit the information the client can share, make them reluctant to respond, and/or increase the risk they may agree with a

practitioners' statement because they are given limited time and response options to respond.

- 19.7 Practitioners should ask for, and accommodate to the extent possible, the client's communication preferences.
  - Practitioners be supportive of client's who use augmentative and alternative communication (AAC) systems, such as by ensuring the client has adequate time to communicate, that they are familiar with a range of communication methods, and that the client can use their preferred method/s throughout all assessment activities (e.g., interview, standardised tests).
  - Practitioners should consider the use of both synchronous (e.g., talking in-person in real time) as well as asynchronous (e.g., providing a set of questions and giving the client time to think about and write a response at the next appointment) communication to cater for different strengths, needs, and/or preferences.
- 19.8 Practitioners should ensure that interpreter, translator, and cultural support services (e.g., Aboriginal health worker) are available when the practitioner, client, and other stakeholders do not speak the same language, including Aboriginal and/or Torres Strait Islander languages and sign language.

#### **Recommendation 20**

#### **Consensus-Based Recommendation**

Practitioners should collect assessment information by observing the way the client interacts with other people and the world around them in clinical and/or community settings.

Grade of Recommendation: Strong

#### **Good Practice Points:**

- 20.1 Practitioners should observe the way the client interacts with other people and their environment across contexts.
- 20.2 Observations may occur in-person, live via telehealth, or via pre-recorded video.
- 20.3 Practitioners may work with others to create opportunities for the client to demonstrate skills, behaviours, and preferences that are relevant to the assessment.

#### **Recommendation 21**

#### **Consensus-Based Recommendation**

Practitioners should collect assessment information by consulting with all relevant stakeholders to collect information that relates to the referral and/or assessment.

#### **Good Practice Points:**

21.1 Practitioners should collect and consider information from all relevant practitioners and other stakeholders (e.g., family members, teachers), including via discussion and review of current and prior reports.

#### **Recommendation 22**

#### **Consensus-Based Recommendation**

Practitioners should consider using, but not rely solely on, standardised assessment, to support clinical decision making in relation to referral, Assessment of Functioning, Medical Evaluation, and Diagnostic Evaluation.

▶ Grade of Recommendation: Strong

- 22.1 Practitioners should consider a client's age, cognitive abilities, spoken language ability, gender, and cultural background when selecting assessment tools, including questionnaires and standardised tests.
- 22.2 When using standardised tests, practitioners should:
  - Ensure that tests are appropriate, including in relation to psychometric properties, as well as considering accessibility (test-taking) challenges that may be associated with communication and intellectual and physical functioning.
  - Practitioners should know what concepts are being assessed by each tool, and the extent to which they will contribute information that is relevant to the purpose of the assessment.
  - Be aware of the limitations of standardised assessments from a cultural perspective, including where they have not been developed, validated, and/or normed with a population relevant to the client, and therefore may be inaccurate, misleading, invalid, and/or otherwise inappropriate.
- 22.3 Practitioners should not use standardised diagnostic tests solely, or as a substitute, for clinical decision making and diagnostic formulation that considers all relevant sources of evidence.
- 22.4 Practitioners should be aware of evidence that some clients report structured questionnaires and tests to be limiting, confusing, and/or frustrating when it comes to sharing information, such as in relation to strengths, needs, and preferences.

### How should information be shared?

Information should be shared with clients at each stage of assessment and diagnostic process in a timely, helpful, and respectful manner. Practitioners should ask for, and accommodate to the extent possible, the client's needs and preferences in terms of information sharing. It is important for practitioners to not make assumptions about how much a client may know about and/or feel about a diagnosis of autism, or project their own feelings about autism to the client. For example, one client may be concerned or apprehensive about a diagnosis while another may feel relieved, validated, and assured. In all instances where information is being shared, practitioners should actively listen to the client, provide ample opportunities for them to ask questions and share feedback, and work together to understand and answer their questions as quickly and clearly as possible.

#### **Recommendation 23**

#### **Consensus-Based Recommendation**

Practitioners should meet with the client and provide information that addresses their reason for accessing the assessment, including diagnostic outcome and to better understand their strengths, needs, and support options.

▶ Grade of Recommendation: Strong

#### **Good Practice Points:**

- 23.1 The documenting and sharing of information, including recommendations for further referral and/or support where appropriate, should be tailored to address the needs of each client including their reason/s for seeking the assessment.
- 23.2 Practitioners should avoid assumptions about what information and recommendations the client may find helpful and important, and instead ask them for their preferences.
- 23.3 Practitioners should encourage the client to ask questions, and provide options for follow-up where possible, so that the client has time to reflect on the information provided.

#### **Recommendation 24**

#### **Consensus-Based Recommendation**

Practitioners should document the assessment process and outcome, including their clinical judgements, recommendations, and support options.

▶ Grade of Recommendation: Strong

#### **Good Practice Points:**

- 24.1 Practitioners should provide the client with a written report about the process and outcomes of the assessment/s.
- 24.2 Practitioners should make practical recommendations that are likely to be feasible for the client, including identifying possible directions for support.
- 24.3 The format, content, structure, and presentation of the report, including the language used to talk about autism, should be discussed with the client and tailored to the extent possible to their specific needs and preferences.
- 24.4 Practitioners should be aware that providing a client with a written report, prior to sharing the findings of an assessment in-person or via telehealth, can be challenging and distressing for some clients, and can convey a sense of disregard for their feelings and aspirations.

#### **Recommendation 25**

#### **Consensus-Based Recommendation**

Practitioners should share information with the client in a way that is timely, accurate, accessible, and appropriate.

▶ Grade of Recommendation: Strong

#### **Good Practice Points:**

- 25.1 Practitioners should discuss with the client how information will be shared and come to an agreement regarding the approach in advance.
- 25.2 Sharing information in a timely manner includes:
  - Regularly sharing information about the assessment process with the client, including next steps.
  - Sharing information about the outcomes of the assessment with the client in a timely manner that prioritises the client's wellbeing. This should be within 3-months of the appointment.

25.3 Sharing information accurately includes:

- Conveying the client's strengths, needs, context, history, future goals, and service preferences in a precise and complete manner, and extending this approach to sharing their professional observations, clinical judgements, and recommendations.
- Communicating in a clear and sensitive manner, both during the collection of information and in sharing the outcome of assessments.

25.4 Sharing information in a way that is accessible includes:

- Accommodating the client's strengths (e.g., information in tables versus text), functioning (e.g., literacy), and preferences (e.g., summarised versus detailed, inperson discussion versus telehealth).
- Frequently checking in with the client to see if the information has been understood and that the information meets their needs.

25.5 Information should be shared in ways that are appropriate for the client. Practitioners should:

- Communicate findings of the assessment in a comprehensive, meaningful, compassionate, and understandable way to the client.
- Share information, including assessment findings, using explanations and language that are strengths-focused and neurodiversity-affirming, balanced with an objective summary of challenges and needs.
- Ensure that when working with Aboriginal and/or Torres Strait Islander peoples or other cultural groups, they involve, when desired by the client, health workers (e.g., Aboriginal health worker), carers, teacher aides, cultural workers and/or clinicians from the time the referral is received through to the assessment findings being communicated and the client being connected to support services.
- To the extent possible, ensure that interpreter services and translated educational materials be made available for all clients from a non-English speaking background.

#### **Recommendation 26**

#### **Consensus-Based Recommendation**

Practitioners should share information with other practitioners in relation to referral, Assessment of Functioning, Medical Evaluation, and/or Diagnostic Evaluation; as well as to help inform the planning and delivery of supports.

• Grade of Recommendation: Strong

- 26.1 Where consent has been given, practitioners should share the findings of the assessment, when appropriate, with other stakeholders such as the referrer, service providers, and funding agencies.
- 26.2 Practitioners should only share information that is relevant with other stakeholders.

## When should referral for health, education, disability, social, and/or community supports be considered?

Referral for support can happen at any time during the assessment process and can include (a) referral to subsequent stages of the assessment and diagnostic process and/or (b) referral to community services and supports. Practitioners should be familiar with supports that are appropriate for the clients with whom they work, including, to the extent possible, the referral process, waitlists, and costs if relevant. Practitioners should also be aware of resources and supports designed and delivered by autistic individuals for the autistic community and make clients aware of these where appropriate.

#### **Recommendation 27**

#### **Consensus-Based Recommendation**

Practitioners should refer the client to appropriate support as soon as a need is identified.

• Grade of Recommendation: Strong

- 27.1 Practitioners should be aware and respectful of the client's goals and aspirations.
- 27.2 Practitioners should consider the client's current support/s, whether these should be maintained, and if additional support/s may be appropriate, at every stage of the assessment and diagnostic process.
- 27.3 Practitioners should refer for supports when a need is indicated, not based on the presence or absence of one or more diagnoses.
- 27.4 Practitioners should have knowledge of the range of supports available and provide the client with information to make an informed decision about supports they may choose to access (e.g., by giving information booklets to review independently, suggesting informal and formal social support networks/groups, sharing information about appropriate individual or group therapy based on identified support needs).
- 27.5 Practitioners should recommend services and supports that are culturally appropriate, affordable, accessible, and feasible in the context of the client's life, resources, location, and community.
- 27.6 Practitioners should ensure that a client receives cultural support from a community member or appropriate professional (e.g., Aboriginal health worker) if this is requested or identified as potentially beneficial during the assessment. This support should be available from the receipt of referral through to the communication of assessment findings and connection to support services.
- 27.7 Practitioners should be aware that clients will have their own unique support networks, which may include partners, parents, guardians, family, and friends.

# How should the quality and safety of assessment and diagnostic services be optimised?

Practitioners have a responsibility to ensure that the services they provide are of high quality and safe for clients who access them. At the heart of this responsibility is the ethical responsibility practitioners have to act in the client's best interests; including ensuring each client understands their options, can make informed decisions, and can provide and withdraw consent if they desire. Creating a safe, high-quality service requires safe physical environments in which assessment can occur, and policies and practices that are effective in identifying and managing risks. The services practitioners offer, should comply with relevant legislative, regulatory, and professional practice requirements and reflect a commitment to human rights consistent with National and International Conventions. Fundamentally, practitioners have a responsibility to work with, support, and respect each client for who they are, why they seek assessment and/or supports, and their right to come to their own understanding of autism.

#### **Recommendation 28**

#### **Consensus-Based Recommendation**

Practitioners should ensure that the client is aware of their service and support options at each stage of the assessment and diagnostic process.

▶ Grade of Recommendation: Strong

- 28.1 The client should be given a clear outline of the services they are being offered including:
  - What will occur.
  - The names, roles, professional qualifications and experience, and responsibilities of each person involved, including the primary contact person.
  - The location, costs, time commitment, and expectations of the client and any other person they involve in the assessment.
  - The expected outcomes (e.g., assessment, written report) and timeframe.
- 28.2 Practitioners should ensure that clients are aware of the options at each stage of referral and assessment, including in relation to who is involved, what and how information will be collected, how information will be shared, and support options that may be appropriate.
- 28.3 Practitioners should ensure that the client is aware of their right to seek another opinion in relation to any element of the assessment and diagnostic process.

#### **Consensus-Based Recommendation**

Practitioners should ensure that the client and/or their legal guardian provides consent for services received and referrals and can withdraw the consent at any time.

▶ Grade of Recommendation: Strong

#### **Good Practice Points:**

- 29.1 Practitioners should ensure that the client, and where appropriate a legal guardian, can provide consent for all services received and understand they can withdraw this consent at any time.
- 29.2 Where a client communicates primarily and/or completely in ways other than spoken and/or written language, such as through the use of augmentative and alternative communication (AAC), practitioners should support decision-making using this modality. However, practitioners should also be aware that some forms of partner-assisted communication (e.g., Facilitated Communication) have demonstrated risks that messages communicated may be those of the partner, not the client, and are not recommended by relevant peak bodies (e.g., Speech Pathology Australia).
- 29.3 Where a client is unable to provide consent due to age, cognitive ability, or a health condition the practitioner should monitor for indications of the client's assent to services provided, including indications that assent has not been provided or has been withdrawn.

#### **Recommendation 30**

#### **Consensus-Based Recommendation**

Practitioners should inform the client of any potential or actual conflicts of interest they may have in providing assessment services or making referrals.

▶ Grade of Recommendation: Strong

- 30.1 Practitioners should recognise and carefully consider all actual and potential conflicts of interest they may have in the provision and recommendation of services and disclose these as appropriate to the client.
- 30.2 Practitioners should ensure that all services for which they receive financial or other compensation are justified and appropriate for the client and are not excessive or unnecessary.
- 30.3 Where a practitioner provides a recommendation and/or referral to another practitioner or service provider, all actual and potential conflicts of interest between the recommending/referring and the receiving practitioner or service provider should be declared to the client.
- 30.4 Practitioners should ensure that recommendation and/or referrals are based on objective criteria and are appropriate for the needs of the client.

- 30.5 Practitioners should take steps to reduce conflicts of interests with recommendations and referrals, including:
  - Establishing ways of monitoring referral practices.
  - Identifying or making alternative referrals when conflicts cannot be appropriately managed.

#### **Consensus-Based Recommendation**

Practitioners should ensure that assessment services are delivered in safe environments.

• Grade of Recommendation: Strong

- 31.1 Practitioners should work to create environments that are comfortable and safe for the client, including:
  - Being aware of any known environmental factors (e.g., loud noises, bright lights) that may cause distress to the client and take appropriate steps to manage these risks.
  - Creating accessible clinical environments, such as avoiding potential sources of sensory discomfort when choosing lighting, furnishings, and materials.
  - Ensuring the client's preferred ways of communicating are supported.
  - Ensuring there are adequate rest breaks.
  - Incorporating the client's interests and preferences, where possible.
- 31.2 Where services are provided in community settings, practitioners should seek input from the client and relevant stakeholders about the suitability of those environments in terms of client and practitioner safety, wellbeing, and privacy.
- 31.3 Practitioners should only conduct assessments in settings that meet the work health and safety requirements set out in the relevant Acts and Regulations in their State or Territory.
- 31.4 Practitioners should establish and follow a risk assessment procedure that:
  - Identifies and documents organisational risks.
  - Uses data to support risk assessments.
  - Acts to reduce risks.
  - Regularly reviews and acts to improve the effectiveness of the risk management system.
  - Reports on risks to the workforce and people accessing their services.
  - Plans for, and manages, internal and external emergencies and disasters.
- 31.5 Practitioners should be aware that the following restrictive practices can present human rights infringements, and should only be used as a last resort and in compliance with relevant State and Territory requirements and regulatory

frameworks, such as the NDIS (Restrictive Practices and Behaviour Support Rules, 2018)

- Seclusion sole confinement of a person with disability in a room or a physical space at any hour of the day or night where voluntary exit is prevented, or not facilitated, or it is implied that voluntary exit is not permitted.
- Chemical restraint the use of medication or chemical substance for the primary purpose of influencing a person's behaviour (not including the use of medication prescribed by a medical doctor for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness, or a physical condition).
- Mechanical restraint the use of a device to prevent, restrict, or subdue a
  person's movement for the primary purpose of influencing a person's behaviour
  but does not include the use of devices for therapeutic or non-behavioural
  purposes.
- Physical restraint the use or action of physical force to prevent, restrict or subdue movement of a person's body, or part of their body, for the primary purpose of influencing their behaviour (not including the use of a hands-on technique in a reflexive way to guide or redirect a person away from potential harm/injury).
- Environmental restraint a restraint restricts a person's free access to all parts of their environment, including items or activities.
- 31.6 Practitioners should be aware of the status of health and safety screenings that are relevant to their work (e.g., Working with Children Check, Disability Worker Screening), and share these with the client if requested.

#### **Recommendation 32**

#### **Consensus-Based Recommendation**

Practitioners should work in ways that support the client's emotional and mental health.

• Grade of Recommendation: Strong

- 32.1 Practitioners should provide a trauma-informed approach; this includes but is not limited to the following:
  - Practitioners should know how trauma may appear in an autistic client.
  - Know the appropriate actions to take should the practitioner suspect abuse by engaging in the proper protection processes.
  - Practitioners should know the options for supporting clients who appear with evidence of trauma.
- 32.2 Practitioners should consider the following in relation to co-occurring mental health conditions:
  - Practitioners should be aware of the autism-specific presentations of mental health conditions, particularly autism-specific manifestations of anxiety, eating, and mood disorders.

- Practitioners should understand the factors that may contribute to developing a mental health condition.
- When a client shows signs of mental health condition/s, practitioners should screen or provide referrals for mental health assessments and/or relevant supports.
- 32.3 Practitioners should be aware that some mental health conditions may result from undiagnosed and/or unsupported autism.
- 32.4 Practitioners should ask the client about their support networks, including those available following a Diagnostic Evaluation, to ensure they have support where possible and are aware of some services that are available if for them (e.g., Lifeline, Carer Gateway, autism-specific organisations).

#### **Consensus-Based Recommendation**

Practitioners should inform the client about how they can provide feedback and make complaints about the services they receive.

Grade of Recommendation: Strong

- 33.1 Practitioners should have a feedback and complaints procedure, which is documented and shared with client prior to the provision of any services.
- 33.2 Where relevant, practitioners should inform the client of their right to make complaints to the National Disability Insurance Scheme Quality and Safeguards Commission.
- 33.3 Practitioners should share and discuss the feedback and complaints procedure in a way that is informative, understandable, and meaningful to the client.
- 33.4 Complaints should be acknowledged, assessed, and resolved in a fair, efficient, and timely manner.
- 33.5 Practitioners should ensure that making a complaint does not adversely affect the provision of services to the client.
- 33.6 If required, the practitioner may need to refer the client to another appropriate practitioner.
- 33.7 Practitioners should ensure that the person making the complaint is:
  - Appropriately involved in the resolution of the complaint.
  - Kept informed of the progress of the complaint, including any action taken and reasons for the decisions made.

#### **Consensus-Based Recommendation**

Practitioners should follow relevant international conventions, national and state/territory legislative requirements, and other associated principles, standards, and frameworks.

► Grade of Recommendation: Strong

#### **Good Practice Points**

- 34.1 Practitioners should be aware of, and work in ways that are consistent with, and not limited to:
  - The United Nations Convention on the Rights of the Child (1989).
  - The United Nations Convention on the Rights of Persons with Disabilities (2006).
  - The United Nations Universal Declaration of Human Rights (1948).
  - The Australian Human Rights Commission Act 1986
  - Where available, the Human Rights Act for the State/Territory in which they work (e.g., ACT Human Rights Act, 2004; QLD Human Rights Act, 2019; The Victorian Charter of Human Rights and Responsibilities Act (2006))
  - The Disability Discrimination Act (1992), including the Disability Standards for Education (2005).
  - The National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measures) Act (2022).
  - The Child Safe Organisations: National Principles for Child Safe Organisations (Australian Human Rights Commission, 2018).
  - National Framework for Protecting Australia's Children (Commonwealth Government of Australia, 2009b).
  - Aboriginal and Torres Strait Islander Early Childhood Strategy Commonwealth Government of Australia (2021).
  - The operational guidelines of the National Disability Insurance Scheme, including the Code of Conduct (2019), and Practice Standards and Quality Indicators (2021).
  - The requirements for working with children, including criminal history screening, as set out in the relevant Acts and Regulations in their State or Territory.
  - The work health and safety requirements set out in the relevant Acts and Regulations in their State or Territory.
  - The National Children's Mental Health and Wellbeing Strategy (2021).

#### **Recommendation 35**

#### **Consensus-Based Recommendation**

Practitioners should be familiar with, and respect, the client's individual language and terminology preferences.

Grade of Recommendation: Strong

#### **Good Practice Points**

- 35.1 Practitioners should ask the client about their preferences and adopt these during all aspects of their work together, including during interactions, in documentation (e.g., progress notes), and in communication about the client (e.g., written reports).
- 35.2 When the client does not have preferences regarding language, practitioners should consider views on language and terminology from the autistic and autism community.
- 35.3 Practitioners should be aware that the client may have different preferences regarding language and terminology, including in relation to talking about autism (e.g., identity-first, person-first), functioning (e.g., differences, impairments), and supports (e.g., therapies, supports, interventions).

#### **Recommendation 36**

#### **Consensus-Based Recommendation**

Practitioners should respect each for who they are; respect their goals, values, and preferences; and work in ways that promote and protect their human rights.

► Grade of Recommendation: Strong

- 36.1 Practitioners should ensure that each client is aware of their human rights.
- 36.2 Practitioners should promote and protect individual rights, including freedom of expression, self-determination, and decision making.
- 36.3 Practitioners should respect the rights of the client to exercise choice and control about matters that affect them.
- 36.4 Practitioners should work in ways that makes the client feel safe, secure, and supported.
- 36.5 Practitioners should work in ways that help the client develop their sense of selfworth and confidence in their self-identity.

## Section 3: Making a Referral for Assessment

Recognising characteristics of autism, and promptly referring, are important to clients receiving timely assessment and access to supports. A range of people may help to identify autism characteristics including parents and caregivers, partners, family, friends, teachers, colleagues, and primary healthcare practitioners. In some cases, clients will already be receiving supports from one or more practitioners for related, or unrelated needs, and it will be through these interactions that the potential relevance of a diagnosis of autism will become apparent. Older children, adolescents, and adults may self-identify characteristics that they feel are consistent with autism. Irrespective of who identifies the potential relevance of an assessment, it is important that they are listened to, and their views are taken seriously.

## When should a referral for autism assessment be initiated?

Typically, when a person shows characteristics of autism, a referral for assessment is recommended. However, there are some circumstances in which the individual may choose not to seek assessment. For example, it is possible that an adult may self-identify as being autistic, based on their own research and reflection, but not want to seek a formal diagnosis. In such cases, it is important to document that a referral was recommended but that the client's wishes for non-referral were respected. Where a referral is made, the practitioner should provide the client with information about the assessment and diagnostic process and service options that are available, including information about the nature of the services, waiting lists, and costs where these are known.

#### **Recommendation 37**

#### **Consensus-Based Recommendation**

Practitioners should refer a client for a Comprehensive Needs Assessment and/or Diagnostic Evaluation, when a potential need is identified.

► Grade of Recommendation: Strong

- 37.1 Practitioners should, when possible, provide the client with options for suitably qualified and experienced practitioners they can be referred to who are appropriate to their circumstances.
- 37.2 Referrals should be made when a need is identified by the client or practitioner, unless the client declines.
- 37.3 Practitioners should be aware that different clients will present with different needs and preferences regarding referral for assessment. Possible reasons for seeking assessment include clients:

- Wanting to better understand themselves, their life experiences, and their support needs.
- Wanting to access support.
- 37.4 Practitioners should consider what, if any aspects, of assessment have already been completed (e.g., Assessment of Functioning) in determining the next stage in the assessment and diagnostic process to refer for.
- 37.5 Practitioners should be mindful to minimise the need for clients to repeat information when seeking a referral to help them feel heard and minimise potential trauma.
- 37.6 Practitioners should be aware of evidence that 'feeling heard' and 'being believed' are of concern to autistic people and family members.

### Who should initiate a referral for autism assessment?

Primary healthcare providers are clinicians who provide the first point of contact within the health system for community members with health concerns. While most Australians will receive primary health care through their general practitioner, primary healthcare providers may also be nurses (including general practice nurses, community nurses and nurse practitioners), allied health professionals, midwives, pharmacists, dentists and Aboriginal health workers.

#### **Recommendation 38**

#### **Consensus-Based Recommendation**

A referral for an assessment for autism should be initiated by a primary healthcare provider.

Grade of Recommendation: Strong

#### **Good Practice Points**

38.1 The professional discipline of the individual initiating a referral may differ between private and public healthcare settings, but they may need to meet specified professional requirements (e.g. be a general practitioner) to meet certain funding conditions, such as for Medicare.

### What information should be collected?

The practitioner should collect information that helps them understand the client and their context, to determine whether a referral for assessment may be appropriate and desirable to them. Practitioners should consider the client's characteristics, functioning, and context, including strengths and support needs, when considering a referral. In children, administration of standardised developmental screening measures can be helpful. If the findings from a developmental screening measure (or developmental history in the case of older clients) suggest that further clinical assessment may be appropriate, it may be helpful

to obtain information about autism characteristics using a screening tool that specifically examines these characteristics. The decision to refer a client for assessment requires clinical judgement based on all information collected.

#### **Recommendation 39**

#### **Consensus-Based Recommendation**

Practitioners should collect information that helps them understand whether a referral for assessment that considers autism may be appropriate and desirable to the client.

▶ Grade of Recommendation: Strong

#### **Good Practice Points**

- 39.1 Practitioners should collect information that will help them understand and document the client's:
  - Characteristics, functioning, and context, including strengths and support needs
  - Views and preferences about if, and why, a referral for assessment may be appropriate and/or desired.
  - Previous contact with practitioners in relation to autism and/or related conditions, including the outcomes of any consultations.
- 39.2 Where a practitioner uses a screening tool to support their gathering of information and decision making (autism-specific screener or broader), they should be aware that screening tools should not be used in isolation to determine whether a client should be referred for an assessment.

## What should be the outcome once a referral for assessment has been considered?

When further assessment is indicated, the next step for the primary healthcare provider is to discuss the rationale with the client and ask if they would like to proceed with a referral. It is possible that practitioners and clients may, at times, disagree as to whether a referral is needed. In such cases, the practitioner should seek and be sensitive to the client's views, and attempt to resolve disagreements through further discussion and clarification. In making a referral, the practitioner should match the client with one or more specified practitioners to conduct the Comprehensive Needs Assessment and Diagnostic Evaluation.

#### **Recommendation 40**

#### **Consensus-Based Recommendation**

Where a need for a diagnostic evaluation is established, the practitioner should make an appropriate referral.

► Grade of Recommendation: Strong

- 40.1 If an assessment that considers autism indicates characteristics consistent with an autism diagnosis, the practitioner should refer the client to the most appropriate practitioner and/or service/s within the assessment and diagnostic process.
- 40.2 Situations can arise where the practitioner who has completed the screening, is also qualified to complete an Assessment of Functioning, Medical Evaluation, and Diagnostic Evaluation. Although they may conduct one or more of these aspects, a referral to at least one other practitioner to help inform the Assessment of Functioning and Diagnostic Evaluation is recommended.
- 40.3 Practitioners should communicate the reason for referral to the client and inform them of their service options including waiting lists and costs if known.
- 40.4 Practitioners should communicate the possible outcomes of a referral to the client, including, but not limited to:
  - The client receiving a diagnosis for one or more conditions.
  - The client not receiving a diagnosis of one or more conditions.
  - Better understanding their strengths and needs, including support options if appropriate, irrespective of whether a diagnosis is given.
- 40.5 A referral for assessment that will consider a possible diagnosis of autism should be made in writing and include:
  - The name of the practitioner to receive the referral.
  - The primary healthcare provider's name, job title, and contact details.
  - Basic demographic information of the client being referred for assessment, including name, age, gender, caregiver (if appropriate) and contact details.
  - The reason for referral, including a description of autism characteristics and any concerns regarding health and functioning that have been reported by the client and/or observed by the primary healthcare provider. This information can include the results of any standardised autism-specific and/or broader screening tools.
  - Details of any existing diagnosis and results of any investigations conducted.
  - Details of any barriers the client may have in accessing the service they are being referred to, such as attending appointments or requiring access to an interpreter.
  - A list of existing reports provided with the referral.
  - Details of any support services that have been established to address urgent support needs identified during the referral process.
- 40.6 While awaiting further assessment, the referring practitioner should provide support to the client where appropriate and feasible.

#### **Consensus-Based Recommendation**

When a practitioner receives a referral, they (or their delegate) should explain the service they offer, indicative costs, book an appointment, and collect appropriate information.

► Grade of Recommendation: Strong

- 41.1 Once a referral is received, the practitioner (or a person to whom they delegate) should contact the client to explain the service and, if appropriate, make an appointment. The information they provide should include:
  - The services offered including costs, time requirements, and what to expect.
  - The name/s, role/s, and responsibilities of staff who will be involved.
  - The role/s and responsibilities of the client in accessing the service (e.g., expectations regarding appointments and involvement in the assessment process).
  - Expected outcomes of the service (e.g., a Diagnostic Evaluation and written report).
  - Resources and supports that are available for people with accessibility needs.
- 41.2 Where a service involves multiple practitioners and/or administrative and support staff, a single person should act as the contact person for the client. The role should include:
  - Sharing the information above.
  - Providing the details of the contact person (e.g., name, email, and direct phone line).
  - Facilitating the client completing any intake, consent and/or self-report forms requested by practitioners before their first meeting.
  - Collecting copies of existing reports from the client, or from other practitioners with the client's consent.
  - Scheduling the first appointment within three months of the referral.
  - Reminding the client of appointment details and to bring completed forms and other requested documents to maximise attendance rates and the information available.
  - Explaining that the client can ask the contact person questions at any time, and that these will then be answered by the most appropriate practitioner.

## Section 4: Comprehensive Needs Assessment

The Comprehensive Needs Assessment comprises an Assessment of Functioning and a Medical Evaluation. The Assessment of Functioning is usually completed by one or more medical or allied health practitioners who have specified qualifications and expertise in assessing a client's functional capacity and needs in everyday activities. The Medical Evaluation is completed by a medical practitioner or appropriately qualified nurse practitioner. However, on occasions, the two elements of the Comprehensive Needs Assessment may be completed by a single practitioner with appropriate qualifications, to expedite the process for clients and avoid repeat assessments. While the Comprehensive Needs Assessment is critical to informing a Diagnostic Evaluation, either one or both elements (i.e., Assessment of Functioning, Medical Evaluation) may be conducted and/or repeated at any time there is a change in the client's needs or circumstances.

## When should an Assessment of Functioning be conducted?

An Assessment of Functioning should be conducted when a diagnosis of autism is being considered and may be repeated any time there is a change in the client's needs or circumstances.

#### **Recommendation 42**

#### **Consensus-Based Recommendation**

Practitioners should conduct an Assessment of Functioning when a diagnosis of autism is being considered.

▶ Grade of Recommendation: Strong

- 42.1 An Assessment of Functioning may be initiated by the client themselves, other stakeholders, or recommended by the practitioner.
- 42.2 The findings of an Assessment of Functioning are critical to informing a Diagnostic Evaluation where autism is being considered.
- 42.3 The Assessment of Functioning should be recent, such that the findings reflect the client's strengths, needs, and context at the time the Diagnostic Evaluation takes place. However, earlier assessment/s of functioning (e.g., report from an occupational therapist earlier in life) should also be considered within the Diagnostic Evaluation.
- 42.4 When used to inform a Diagnostic Evaluation, the Assessment of Functioning should include consideration of characteristics that are relevant to the differential diagnosis of autism and other conditions.

#### **Consensus-Based Recommendation**

An Assessment of Functioning should be conducted, if relevant, at multiple points throughout the individual's life to ensure that changes to level of functioning and support needs are identified and acted on in a timely manner.

▶ Grade of Recommendation: Strong

#### **Good Practice Points**

- 43.1 Further assessment can be conducted as required by clinicians engaging with the client at the particular time.
- 43.2 A client may benefit from repeating an Assessment of Functioning at multiple relevant time points, as their characteristics, functioning, context, strengths, and support needs change with age and stage of life.

### Who should conduct an Assessment of Functioning?

Assessment of Functioning should be conducted by medical, nurse, and/or allied health practitioners with specified qualifications, with input from all relevant stakeholders. To enable flexibility within the assessment and diagnostic process, the choice of practitioner/s who conduct the Assessment of Functioning is decided by the Assessment Team.

#### **Recommendation 44**

#### **Consensus-Based Recommendation**

An Assessment of Functioning should be conducted by medical, nurse, and/or allied health practitioners with specified qualifications, with input from all relevant stakeholders.

► Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

- 44.1 One or more practitioners from specified different disciplines may contribute to an Assessment of Functioning, either individually (with the findings shared) or as a team.
- 44.2 The Assessment of Functioning should be conducted by a practitioner or practitioners meeting one or more of the following eligibility criteria:
  - Medical practitioner who holds general or specialist registration with the Medical Board of Australia.

- Nurse practitioner who holds general registration with the Nursing and Midwifery Board of Australia and is endorsed as a nurse practitioner or as a registered nurse with relevant experience as a clinical nurse specialist/consultant.
- Occupational therapist who holds registration with the Occupational Therapy Board of Australia.
- Psychologist who holds general registration, with or without a practice endorsement, with the Psychology Board of Australia.
- Social worker who is eligible to be a member of the Australian Association of Social Workers
- Speech pathologist who is eligible to be a Certified Practicing Member of Speech Pathology Australia.

# What information should be collected as part of an Assessment of Functioning?

The determination of individual functioning and support needs requires the collection of a range of information appropriate to the client. The International Classification of Functioning, Disability, and Health (World Health Organisation, 2001) sets out a series of activity and participation domains that are relevant to consider:

- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self-care
- Domestic life
- Interpersonal interactions and relationships
- Major life areas
- Community, social, and civic life.

#### **Recommendation 45**

#### **Consensus-Based Recommendation**

Practitioners should collect information in the Assessment of Functioning that helps them understand the client's characteristics, functioning, and their context, including their strengths and support needs, across life activities.

• Grade of Recommendation: Strong

#### **Good Practice Points:**

- 45.1 An Assessment of Functioning that is used to inform a Diagnostic Evaluation for autism should cover a range of broad developmental areas and ICF domains (World Health Organisation, 2001).
- 45.2 Practitioners should adopt a strengths-based approach in all aspects of the Assessment of Functioning, including when collecting information and sharing and reporting the findings.
- 45.3 An Assessment of Functioning may include information provided by the client and where appropriate and consented, other stakeholders, for example:
  - Experience and outcomes with education (e.g., insights from teachers and school reports).
  - Experiences and outcomes at work (e.g., insights from work colleagues and performance reviews).
  - Independent living skills (e.g., insights from support workers and home adjustments).

45.4 Information that may be appropriate to collect includes:

- Medical and health history: Information from the antenatal, perinatal, neonatal, past and current periods in relation to hearing, vision, physical, and mental health conditions.
- Family history and family function: Presence of medical, psychiatric and neurodevelopmental conditions (including autism) among immediate and extended family members as well as social and environment factors (e.g., family violence, substance abuse, neglect and trauma, support networks)
- Developmental and educational history: How the client has presented during their lifetime in terms of early developmental milestones for cognition, communication, social, and gross/fine motor and personal care skills as well as the presence of any developmental regression.
- Autism-specific characteristics: Reported and observed experiences, preferences, and behaviours relating to social communication/interaction and restricted, repetitive patterns of behaviour outlined in either the current DSM-5-TR or ICD-11 diagnostic criteria.
- Functioning and participation in life activities.
- Other characteristics and/or behaviours that may indicate the presence of a cooccurring condition and/or differential diagnosis.
- 45.5 Practitioners should consider the aspects of the client (e.g., communication skills, daily living skills), their contexts (e.g., support networks, accessibility of their environments, adjustments in place in their environments), and interactions

between the two, when evaluating, documenting, and reporting the client's functioning.

- 45.6 Practitioners should consider the client's functioning with respect to their current activity demands, as well as contextual factors that act as barriers and/or enablers to functioning.
- 45.7 Practitioners should enquire about changes (including fluctuations) in functioning and support needs the client may experience in different contexts and/or over time, and the extent to which support needs have been met.
- 45.8 Practitioners should be aware of the limitations of using 'levels of support need' specified in the DSM-5-TR to describe a person's level of functioning, including the risks associated with using them to make decisions regarding access to services. Where these levels are used for descriptive purposes, practitioners may use the findings from an Assessment of Functioning to inform the categorisation of 'severity level' (in cases where DSM-5-TR criteria are used) without the need for repeating a Diagnostic Evaluation.

## What should be the outcomes of an Assessment of Functioning?

The Assessment of Functioning should aim to answer the client's questions and help them identify and advocate for their strengths and support needs. It is the responsibility of the practitioner/s conducting the Assessment of Functioning to provide the client with an accurate, holistic, and individualised summary of the findings of the assessment and recommendations for support if appropriate. Where recommendations for referral and/or support are indicated, the practitioner should present the client with options, where possible, as well as information about waiting lists and costs if known.

#### **Recommendation 46**

#### **Consensus-Based Recommendation**

Where support needs have been identified, practitioners should inform the client of their support options and provide a referral if appropriate.

Grade of Recommendation: Strong

- 46.1 Practitioners should document and share information about the client's characteristics, functioning, and context that are relevant to establishing and addressing their support needs.
- 46.2 Where appropriate, practitioners should recommend services and support options that are likely to meet the client's needs and align with their preferences, including

health, education, disability, social, and community services and provide a referral if appropriate.

#### **Recommendation 47**

#### **Consensus-Based Recommendation**

Where the findings of the Assessment of Functioning are consistent with a possible diagnosis of autism, the next step/s in the assessment and diagnostic process should be initiated.

• Grade of Recommendation: Strong

#### **Good Practice Points:**

- 47.1 Practitioners should discuss their findings with the client and recommend that the appropriate next step/s in the assessment and diagnostic process be followed.
- 47.2 Practitioners should explain the process and service options, including financial costs and any waiting periods where this information is known.
- 47.3 Where a client or legal guardian does not wish to pursue further assessment within the diagnostic process, their decision should be documented, and the client informed that they can revisit their decision at a later time if they wish to.
- 47.4 Practitioners should ensure that all information relevant to differential diagnosis, including the findings of any assessment tools used, and the characteristics of autism and other conditions, is documented and available for consideration as part of the Diagnostic Evaluation.

### When should a Medical Evaluation be conducted?

A Medical Evaluation should be conducted when a diagnosis of autism is being considered.

#### **Recommendation 48**

#### **Consensus-Based Recommendation**

Practitioners should conduct a Medical Evaluation as part of a Comprehensive Needs Assessment.

Grade of Recommendation: Strong

- 48.1 The Medical Evaluation should be conducted as soon as a need is identified.
- 48.2 The Medical Evaluation should include consideration of characteristics that are relevant to the differential diagnosis of autism and other conditions.

### Who should conduct a Medical Evaluation?

Flexibility has been incorporated in the assessment model to allow several options in the choice of practitioner/s involved in the Medical Evaluation. Factors that may influence the choice of practitioner include the training and expertise of practitioner/s already involved, and the availability of medical practitioners experienced in the assessment of neurodevelopmental conditions in the local area.

#### **Recommendation 49**

#### **Consensus-Based Recommendation**

Medical Evaluation and investigations relevant to neurodevelopmental and behavioural conditions should be conducted by a medical practitioner who holds general or relevant specialist registration with the Medical Board of Australia.

Grade of Recommendation: Strong

#### **Good Practice Points**

49.1 In addition to holding the relevant qualification, practitioners should have training and expertise in assessment, and experience in the assessment of neurodevelopmental conditions.

#### **Recommendation 50**

#### **Consensus-Based Recommendation**

A medical practitioner may receive assistance in collecting information for the Medical Evaluation from a nurse practitioner who holds general registration with the Nursing and Midwifery Board of Australia and is endorsed as a nurse practitioner or as a registered nurse with relevant experience as a clinical nurse specialist/consultant, practising under appropriate medical supervision.

Grade of Recommendation: Strong

#### **Good Practice Points**

50.1 In addition to holding the relevant qualification, nurse practitioners should have training and expertise in assessment, and experience in the assessment of neurodevelopmental conditions.

## What information should be collected in a Medical Evaluation?

The aim of the Medical Evaluation is to assess whether there are medical causes and/or associations with the behavioural presentation of the client and to contribute to the identification of support needs.

#### **Consensus-Based Recommendation**

Practitioners should gather information that helps them understand the client's health and wellbeing, including identifying needs, characteristics and findings that can inform differential diagnosis and recommendations for support options.

Grade of Recommendation: Strong

#### **Good Practice Points:**

- 51.1 Medical practitioners should gather information on:
  - The client's reason for accessing a Medical Evaluation.
  - Individual health history including:
    - Developmental history and growth status including antenatal, birth and postnatal history including identification of congenital abnormalities and assessing for dysmorphic features.
    - Neurological, general systems, skin, injury, vision, and hearing status.
    - Relevant biological investigations.
    - Chronic medical issues including those with increased incidence in autistic people.
  - Other relevant history including social history and family history.
- 51.2 Medical practitioners should consider, and adequately explore, all concerns raised by the client, including potential medical causes/symptoms and/or associations with the client's behavioural presentation and how these contribute to the identification of support needs.

### What should be the outcomes of a Medical Evaluation?

The Medical Evaluation should aim to answer the client's questions and may be helpful in identifying the need for specialist referrals, assessments, and supports as part of ongoing clinical care. It is the responsibility of the practitioner/s conducting the Medical Evaluation to provide information to the client about the outcomes of the Medical Evaluation and any investigations conducted, including if the findings may be relevant to a diagnosis of autism. The practitioner/s who conducted the Medical Evaluation should discuss their findings and recommendations, including for a Diagnostic Evaluation if warranted.

#### **Recommendation 52**

#### **Consensus-Based Recommendation**

Where health and wellbeing needs have been identified, practitioners should inform the client of their options and provide a referral if appropriate.

Grade of Recommendation: Strong

#### **Good Practice Points:**

- 52.1 Practitioners should discuss their findings with the client and recommend that the next step in the diagnostic process be followed, including referral for support where appropriate.
- 52.2 Practitioners should document the findings of the Medical Evaluation and discuss these with the client.
- 52.3 Practitioners should provide appropriate treatment (if warranted), and/or recommend services and support options that are likely to meet the client's needs and align with their preferences, including health, education, disability, social, and community services.

#### **Recommendation 53**

#### **Consensus-Based Recommendation**

Where the findings of the Medical Evaluation are consistent with a possible diagnosis of autism, the next step in the assessment and diagnostic process should be initiated.

► Grade of Recommendation: Strong

- 53.1 Practitioners should discuss their findings with the client and recommend that the appropriate next step in the assessment and diagnostic process be followed, including referral for support where appropriate. Explanations and language used should be strengths-focused and neurodiversity affirming.
- 53.2 Practitioners should explain the relevant pathways and service options, including waitlists and costs where known.
- 53.3 Where a client does not wish to pursue further assessment within the assessment and diagnostic process, their decision should be respected and documented, with consideration given to revisiting the client's decision at future sessions.
- 53.4 Practitioners should ensure that all information that is relevant to differential diagnosis, including the findings of investigations, and the characteristics of autism and other conditions, is documented and available for consideration as part of the Diagnostic Evaluation.

### **Section 5: Diagnostic Evaluation**

The Diagnostic Evaluation aims to determine if a diagnosis of autism and/or other conditions is appropriate. The Diagnostic Evaluation should be conducted by practitioners with specified qualifications, using a tiered approach, and in a way that helps ensure timely, accurate, and appropriate diagnostic evaluation, sharing and reporting of the findings, and referral for supports where indicated.

### When should a Diagnostic Evaluation be conducted?

A Diagnostic Evaluation should be conducted when autism is indicated as a possible diagnosis.

#### **Recommendation 54**

#### **Consensus-Based Recommendation**

A Diagnostic Evaluation should be conducted when there are indications of autism.

Grade of Recommendation: Strong

- 54.1 Practitioners should explain the potential benefits of undertaking a Diagnostic Evaluation, irrespective of whether they receive an autism diagnosis or not. These may vary for individual clients, but can include:
  - The client gaining a better understanding themself, their experience of interacting with other people and the world around them.
  - Other people better understanding the client's experience, strengths, and needs, irrespective of diagnosis, where the client chooses to share this information following the evaluation.
  - The client feeling better understood and their views and experiences validated.
  - Identifying supports to assist in functioning and enhance wellbeing.
  - Where a differential diagnosis is made, it can be helpful in describing the client's experience, strengths, and needs to other people, including accessing appropriate supports.
- 54.2 Practitioners should explain the potential costs of undertaking a Diagnostic Evaluation. These may vary for individual clients, but can include:
  - Financial costs incurred in attending and paying for services, including for travel and lost earnings.
  - The time that will be required to attend appointments, including travel and time spent away from other work and family activities.

54.3 Some clients may find the process and outcomes of the Diagnostic Evaluation challenging, particularly where different people have different views regarding its relevance. Identifying the potential challenges may help the practitioner, the client, their family and supporters put in place strategies and supports for the emotional wellbeing for all involved.

### Who should conduct a Diagnostic Evaluation?

A Lead Practitioner Diagnostic Evaluation should be conducted by a medical practitioner or psychologist with specified qualifications and relevant knowledge, skills, training, support, and regulation (see Table 2.1). Ideally the choice of practitioner will take into consideration the costs, waiting times, and other resource availability factors. It is recommended that this assessment incorporate input from at least one other practitioner from a different discipline or specialty.

A Consensus Team Diagnostic Evaluation should be conducted by two or more practitioners, with the choices tailored to meet the specific assessment needs of the client. In cases where a Lead Practitioner Diagnostic Evaluation is inconclusive, the practitioner who conducted it will be responsible for determining which other practitioner/s are invited to join the team and/or which team to refer to. In some Australian states and territories, multidisciplinary tertiary services are available for the assessment of clients with complex neurodevelopmental conditions. These services, where available, can also fulfil the role of the Consensus Team Diagnostic Evaluation.

#### **Recommendation 55**

#### **Consensus-Based Recommendation**

The Diagnostic Evaluation should involve practitioners with specified medical and/or allied health qualifications, combined with advanced training and/or experience relevant to the differential diagnosis of autism from a range of neurodevelopmental and behavioural conditions.

Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

- 55.1 Practitioners who lead a Diagnostic Evaluation should have specified allied health and/or medical qualifications and training and expertise in assessment.
- 55.2 A Lead Practitioner Diagnostic Evaluation should be conducted by one practitioner meeting at least one of the following:

- Medical practitioner who holds specialist registration with the Medical Board of Australia in the field of community child health, general paediatrics, psychiatry or neurology.
- Medical practitioner who holds general or specialist registration with the Medical Board of Australia and has at least six years of relevant experience, training or supervision in the assessment of neurodevelopmental and behavioural disorders.
- Psychologist who holds general registration with the Psychology Board of Australia and practice endorsement in clinical psychology, educational/developmental psychology, or neuropsychology.
- 55.3 The decision as to which practitioner will lead a Lead Practitioner Diagnostic Evaluation should take into consideration the costs, waiting times, and availability of other resources to ensure the client has access to assessment in a timely and accessible manner.
- 55.4 Practitioners who lead a Lead Practitioner Diagnostic Evaluation must have knowledge of the role, scope of practice, and when to seek additional information from other practitioners who can contribute to clinical decision making regarding differential diagnosis. The decision of which other practitioner/s to include should be based on their capacity to contribute expertise that can help to address diagnostic uncertainty.
- 55.5 A Consensus Team Diagnostic Evaluation should include at least one additional practitioner who meets at least one of the following eligibility criteria:
  - Medical practitioner who holds specialist registration with the Medical Board of Australia in the field of community child health, general paediatrics, psychiatry or neurology.
  - Medical practitioner who holds general or specialist registration with the Medical Board of Australia and has at least six years of relevant experience, training or supervision in the assessment of neurodevelopmental disorders.
  - Occupational therapist who holds registration with the Occupational Therapy Board of Australia.
  - Psychologist who holds general registration, with or without a practice endorsement, with the Psychology Board of Australia.
  - Speech pathologist who is eligible to be a Certified Practicing Member of Speech Pathology Australia.

#### **Consensus-Based Recommendation**

When a Lead Practitioner Diagnostic Evaluation is conducted, it should involve input from at least one other medical and/or allied health practitioner with specified qualifications.

#### Grade of Recommendation: Conditional

This Recommendation is as important as any other. The 'conditional' rating refers to factors to consider during implementation. Please refer to the Supporting Evidence document for further information.

#### **Good Practice Points:**

- 56.1 Medical and allied health practitioners who are involved in a Diagnostic Evaluation should have appropriate allied health and/or medical and training and expertise in assessment.
- 56.2 In considering which other practitioner/s may be invited to contribute to a Lead Practitioner Diagnostic Evaluation, the practitioner should take into consideration the information that is needed (e.g., practitioner perspectives), practitioners the client is already working with who can provide insights, costs, waiting times, and availability of other resources to ensure the client has access to assessment in a timely and accessible manner.
- 56.3 Practitioners who are involved in a Diagnostic Evaluation must have knowledge of the role, scope of practice, and when to seek additional information from other practitioners who can contribute to clinical decision making regarding differential diagnosis.

#### **Recommendation 57**

#### **Consensus-Based Recommendation**

In circumstances where a Consensus Team Diagnostic Evaluation is warranted but the team is in a geographically distant location to the client's community, a partnership between the team and one or more community practitioners should be initiated.

▶ Grade of Recommendation: Strong

- 57.1 When an Assessment Team is in a geographically distant location to the client's community, it is important that where possible, a local practitioner is nominated to communicate with the client about the assessment process, including the stages of the assessments, outcomes and available supports and resources.
- 57.2 What constitutes a 'geographically distant' location is subjective and the need for a local practitioner to be involved should be made in partnership with the client based on their needs and preferences.
- 57.3 Where indicated, it is important that a local practitioner who knows the client well communicates all relevant findings completed by the local team with the client to ensure that assessments are not repeated, and the client isn't being asked to retell information.

- 57.4 The practitioners from the Assessment Team should also be given any background information required to understand the client within their environment and any enablers and/or barriers specific to the client which may have impacted functional outcomes.
- 57.5 It is important that assessment and communication with the client are set up to suit the needs of the client and are chosen by the client and/or appropriate training is provided in the use of these methods (e.g., online video call, phone call).

## What information should be collected in a Diagnostic Evaluation?

The central aim of a Diagnostic Evaluation is to consider the possibility of autism and other conditions as part of a differential diagnosis. Accordingly, the Diagnostic Evaluation brings together all available information, including the referral, findings from the Comprehensive Needs Assessment, and previous reports, and combines it with the collection of further information that is directly relevant to considering diagnostic criteria for a range of conditions.

The collection of information about autism characteristics through the administration of autism-specific assessments (e.g., Autism Diagnostic Observation Schedule) has been demonstrated to provide considerable assistance in making diagnostic formulations. These instruments provide the benefit of a structured and consistent way of collecting information about the presence and extent of behaviours frequently associated with autism. However, all instruments have limitations in relation to sensitivity (how well a measure correctly identifies individuals as being autistic, when they are indeed autistic) and specificity (how well a measure performs in not identifying a person is autistic, when they are not autistic). A key consideration when evaluating tools relates to the population for whom they were developed, and the extent to which they may be relevant to a particular client, taking into consideration factors such as their age, gender, cognitive level, and cultural background. Appendix 5.1 provides examples of other assessment tools that may be appropriate for assessing core autism characteristics (i.e., social-communication and behaviour) and alternative or co-occurring conditions (e.g., intellectual disability, anxiety)

There is growing awareness of the need to ensure that the information collected as part of a Diagnostic Evaluation is sensitive to differences in how autistic individuals may present, with respect to age, gender, and co-occurring psychosocial needs. Practitioners should be aware that autism characteristics present differently for different people and can fluctuate over time and based on contexts (e.g., high versus low social demands) and environments (e.g., sensory safe versus challenging). Autism characteristics may also be less readily observed in people who adapt their behaviour in line with non-autistic social norms, which is often referred to as 'masking.' It is essential that the unique characteristics and experiences of each client are explored and documented, ahead of considering differential diagnosis.

#### **Consensus-Based Recommendation**

Practitioners should collate information from all appropriate sources including the referral, Assessment of Functioning, and Medical Evaluation for consideration in the Diagnostic Evaluation.

► Grade of Recommendation: Strong

#### **Good Practice Points:**

- 58.1 Practitioners conducting a Diagnostic Evaluation should seek to understand the client first and foremost and their unique reasons for seeking an assessment.
- 58.2 Practitioners should obtain information from a recently completed Assessment of Functioning and Medical Evaluation for the purpose of informing a diagnostic decision.
- 58.3 Practitioners should ensure that other sources of information, such as allied health practitioner reports on the outcomes of support services previously offered, school reports, and information provided formally and/or informally by other relevant stakeholders are considered.
- 58.4 It is important that assessments are not duplicated as part of a Diagnostic Evaluation and clients are not asked to retell information already given to other members of the Assessment Team.

#### **Recommendation 59**

#### **Consensus-Based Recommendation**

Practitioners should gather and/or confirm information about social-communication and behavioural characteristics that are relevant to a diagnosis of autism, as well as characteristics that may inform differential diagnosis of other conditions.

▶ Grade of Recommendation: Strong

- 59.1 Practitioners should gather information that is relevant to a diagnosis of autism and/or other conditions from a variety of evidence sources.
- 59.2 Where autism-specific diagnostic tools are used to collect information, it is essential that the results are considered in context and in relation to the broader set of information gathered, to inform differential diagnosis.

# What information should be considered in making a diagnosis?

All information collected during the assessment and diagnostic process, including from the referral, Comprehensive Needs Assessment and Diagnostic Evaluation should be taken into account when considering differential diagnosis of autism and/or other conditions.

#### **Recommendation 60**

#### **Consensus-Based Recommendation**

Practitioners should take into account the client's characteristics and their impact on functioning individually and in comparison to people of the same chronological and developmental age when considering a diagnosis of autism.

• Grade of Recommendation: Strong

#### **Good Practice Points:**

- 60.1 Practitioners should be aware that the characteristics of autism, and the client's functioning, often varies with age, and therefore should be considered in relation to peers of similar age (children through to adults) and cognitive level.
- 60.2 Practitioners should be aware that to meet DSM-5-TR criteria for autism, the client's social-communication functioning must be considered relative to developmental level, in order to satisfy requirements for differential diagnosis with intellectual disability.

#### **Recommendation 61**

#### **Consensus-Based Recommendation**

Practitioners should take into account potential gender-based differences in the characteristics of autism when considering a diagnosis of autism.

▶ Grade of Recommendation: Strong

#### **Good Practice Points:**

61.1 Practitioners should be aware that:

- The diagnostic characteristics of autism may present differently, and at different times, for clients who are assigned male and female at birth.
- There is accumulating evidence that females are under-diagnosed in the community.
- Autistic clients may 'mask' their individual characteristics and behaviours, by adopting non-autistic approaches to social interaction and behaviour. There is

evidence that masking is more common in females and is detrimental to a client's health and wellbeing.

 There is accumulating evidence that being transgender and gender diverse is more common in autistic children, adolescents and adults compared to the broader population. While the current evidence base does not warrant the recommendation for universal screening of gender diversity in autism Diagnostic Evaluations, the identification of this co-occurrence should trigger a referral to appropriate services with expertise in gender diversity. Sensitivity to genderrelated language should be exercised during assessment. This may be achieved in part by allowing clients to self-describe their gender on initial intake forms and referring to the client by their preferred gender pronoun/s.

#### **Recommendation 62**

#### **Consensus-Based Recommendation**

Practitioners should consider the potential impact of current and/or past psychosocial factors on the client's behavioural presentation and functioning, when considering a diagnosis of autism.

▶ Grade of Recommendation: Strong

#### **Good Practice Points:**

- 62.1 The Diagnostic Evaluation for client's who have complex psychosocial factors requires a more intricate exploration to determine whether characteristics are best explained by autism and/or other personal or environmental factors. Examples of complex psychosocial factors include a history of trauma, neglect, maltreatment, abuse, domestic violence, family breakdown, attachment disruption, refugee status, out-of-home care or incarceration.
- 62.2 Along with potentially overlapping characteristics, complex psychosocial factors may present additional challenges to obtaining complete and accurate information as the basis for differential diagnosis of autism.
- 62.3 Adopting trauma-informed principles may assist practitioners to understand and address complex psychosocial factors.

### How should a diagnostic decision be made?

Reaching a diagnostic decision requires consideration of all available evidence from all stages of the assessment and diagnostic process.

#### **Consensus-Based Recommendation**

Practitioners should use the current versions of either of the following international diagnostic manuals to make diagnostic decisions in relation to autism: the Diagnostic and Statistical Manual of Mental Disorders or the International Statistical Classification of Diseases and Related Health Problems.

• Grade of Recommendation: Strong

#### **Good Practice Points**

63.1 Given diagnostic manuals are regularly updated, practitioners should use the most up to date version of the diagnostic manual available at the time.

#### **Recommendation 64**

#### **Consensus-Based Recommendation**

Practitioners involved in Diagnostic Evaluation should use their clinical judgement to reach their diagnostic decision by taking into account all relevant information from all stages of the assessment and diagnostic process.

▶ Grade of Recommendation: Strong

#### **Good Practice Points:**

64.1 In making a diagnostic decision, practitioners should:

- Take into account all information collected in the Assessment of Functioning and Medical Evaluation.
- Where a Lead Practitioner Diagnostic Evaluation was conducted prior to a Consensus Team Diagnostic Evaluation, information from both evaluations should be considered.
- Integrate and weigh the available evidence against each diagnostic criterion (according to the current version of the DSM or ICD)
- Test alternative explanations for characteristics that may warrant cooccurring or differential diagnosis or alternative clinical pathways.
- 64.2 Where a Lead Practitioner Diagnostic Evaluation is being conducted, the practitioner should consider whether sufficient information is available to make a diagnostic decision with high confidence without proceeding to a Consensus Team Diagnostic Evaluation.

# What should be the outcomes of a Diagnostic Evaluation?

The Diagnostic Evaluation should seek to answer any further questions the client has, and provide them with clear, accurate, and accessible information about the relevance, or not, of a diagnosis of autism and/or other conditions. The practitioner/s should explain their clinical reasoning, any ambiguity that remains, and provide the client with encouragement and ample opportunities to ask questions and discuss the findings, implications, and recommendations for support where these have been made.

If a diagnosis of autism is confirmed, it is essential that the practitioner be sensitive to level of knowledge and individual views of the client, including cultural considerations that may influence their understanding and views about autism. The conversation and subsequent reporting and sharing of the findings should be accurate, strengths-focused, and neurodiversity affirming. The content and language used in reports should be tailored according to their intended purpose (e.g., medical language to access funding versus neurodiversity-affirming language for client's personal interest).

When making a diagnosis of autism using the DSM-5-TR criteria, the practitioner is required to indicate the client's support needs, using a three-point scale for each of the two diagnostic domains (social-communication and behaviour). This appraisal is made based on consideration of all available information and interpretation of the diagnostic criteria. Practitioners should be sensitive to the fact that these decisions are subjective and should disregard any potential implications for funding and/or supports that may arise from their appraisal of the level of support needs and focus solely on their professional responsibility and clinical judgement. The DSM-5-TR states that 'severity' levels may vary by context and also fluctuate over time, and so severity levels should not be used to determine eligibility for, and provision of, services.

It is possible that the client and practitioner/s may disagree regarding the outcome of the Diagnostic Evaluation. In such cases, the practitioner should seek and be sensitive to the client's views, attempt to resolve disagreements through further discussion and clarification, but adhere to their professional responsibilities to provide accurate advice and appropriate recommendations. Where a client disagrees with the diagnostic decision, they have the right to seek another opinion.

#### **Recommendation 65**

#### **Consensus-Based Recommendation**

Practitioners should discuss with the client and document the findings of the Diagnostic Evaluation, including whether a diagnosis of autism and/or other conditions is appropriate.

Grade of Recommendation: Strong

- 65.1 Practitioners may discuss their observations and findings with the client at multiple points throughout the evaluation (e.g., to make explicit their clinical decision making) and/or present the findings once all aspects of the evaluation are complete.
- 65.2 A Lead Practitioner Diagnostic Evaluation will result in one of the following three outcomes:
  - High confidence that the client does not meet diagnostic criteria for autism and/or or another condition.
  - High confidence that the client does meet diagnostic criteria for autism and/or another condition, with noting of current specifiers and level of support needs if DSM-5-TR criteria are utilised.
  - High confidence not yet being achieved as to whether the client meets diagnostic criteria for autism and/or another condition, and a Consensus Team Diagnostic Evaluation is required.
- 65.3 A Consensus Team Diagnostic Evaluation will result in one of the following three outcomes:
  - Consensus reached that the client does not meet criteria for autism and/or another condition.
  - Consensus reached that the client does meet criteria for autism and/or another condition, with noting of specifiers and current level of support needs if DSM-5-TR criteria are utilised.
  - Consensus not being reached as to whether the client meets criteria for autism and/or another condition, and the client being recommended for reassessment at a later time. In this case, it is suggested that all relevant information is provided to the Assessment Team conducting the reassessment (where possible) to avoid unnecessary duplication of services.
- 65.4 Practitioners should provide feedback in a manner that is respectful and addresses the client's unique reasons for seeking a Diagnostic Evaluation.
- 65.5 Practitioners should provide the opportunity for other people important to the client (where desired and with the client's consent) to be present at all times during the Diagnostic Evaluation, including when findings are being discussed, and provide a setting where the client feels comfortable asking questions.
- 65.6 Practitioners should encourage clients to ask questions and facilitate discussion regarding how the diagnostic outcome may affect relationships, roles and eligibility for services/funding.
- 65.7 The information shared, discussed, and then documented in a report, should include:

- Clear confirmation of the diagnostic outcome and a rationale for the diagnostic decision.
- The diagnostic criteria utilised (e.g., DSM-5-TR or ICD-11).
- Evidence that supports the presence or absence of each autism diagnostic criterion.
- Where DSM-5-TR is used, evidence for the current level of support needs and specifiers.
- The assessment tools used, including the name of the instrument, what it measures, the administering professional, the findings, and their implications.
- Current developmental status/level of functioning across multiple domains and potential level of functioning with supports.
- The client's strengths.
- Contextual factors, including barriers and enablers of functioning and participation.
- Co-occurring conditions that have been identified/diagnosed (e.g., dual autism/ADHD diagnosis) or that require further investigation.

#### **Recommendation 66**

#### **Consensus-Based Recommendation**

Practitioners should discuss and document recommendations, including referral for further assessment and/or supports, where appropriate.

Grade of Recommendation: Strong

#### **Good Practice Points**

- 66.1 Practitioners should provide clients with information on available clinical and support services to address functional needs irrespective of whether a diagnosis of autism was given.
- 66.2 Recommendations must be sufficiently detailed for clients to follow, including in relation to further assessments if required, as well as informal and formal supports, and the ways in which these may be accessed including funding mechanisms.
- 66.3 Practitioners should ensure that information is presented in a clear and understandable way, attempt to assess whether the client has understood, and encourage the client to ask any questions they may have.
- 66.4 Practitioners should, to the extent possible, arrange for clients to have access to follow-up support following the Diagnostic Evaluation, regardless of whether a diagnosis of autism was made, to support them in processing the outcome.

# **Future directions**

This Guideline provides an updated set of Consensus-Based Recommendations for assessment and diagnosis of autism in Australia. These Recommendations are relevant to any jurisdiction that is involved in the funding or provision of assessment and diagnostic services related to autism. The next steps are to support the use of the updated Guideline to inform policy and practice and evaluate its use and impact in preparation for future updating.

# Dissemination and implementation of the Guideline

Following the publication of the Guideline, Autism CRC will undertake activities to support the dissemination of the updated Guideline and implementation of the Recommendations. It is envisaged that dissemination activities will include traditional and social media awareness campaigns, email distributions, the development of web resources, and the delivery of workshops and seminars. It is anticipated that these activities will be conducted in close consultation with relevant professional colleges and societies and consumer representative organisations. The Dissemination and Implementation Plan is provided in further detail as a separate document to this updated Guideline.

# **Endorsement of the Guideline**

It is important that national and state-based government departments (e.g., education, disability and health), along with service providers, consider endorsing the Guideline as a minimum clinical standard for autism assessment and diagnosis. In addition, it is important for national peak bodies to consider endorsement of the Guideline to ensure its uptake in clinical practice. Following the publication of the Guideline, Autism CRC will encourage adoption, and where relevant endorsement, of the updated Guideline from the peak clinical and consumer bodies represented on the Reference Group.

# **Future directions for research**

### **Evaluation of the Guideline**

The Guideline, and resources that support its implementation, should continue to be evaluated. Key questions relate to feasibility, acceptability, affordability, use by practitioners, the effect on their practice, and the effect on their clients. This information can inform current and future implementation efforts, as well as future updates of the Guideline.

#### **Guideline update**

The Guideline Recommendations should be reviewed and updated on a regular basis to respond to new evidence from research, clinical practice, and changes in community preferences and priorities. The next update should be within 5 years of publication of this

current update and continue to employ a methodology that meets requirements for approval by the National Health and Medical Research Council. Given there are now two Guidelines to inform professional practice when working with autistic people in Australia, and the potential for more in future, it is important that the processes for updating and implementing Guidelines are coordinated, with the view to creating seamless guidance for practitioners across all aspects of the assessment and diagnostic process.

#### **Evidence gaps**

The research activities identified key knowledge gaps that require urgent research attention. These include:

**Culturally safe practice:** It is important to understand how autism is conceptualised and talked about in culturally diverse communities - including Aboriginal and Torres Strait Islander peoples – to inform the way autism is discussed, assessed, and diagnosed. Furthermore, it is important that culturally safe, relevant, and appropriate assessment tools and practices are developed, including standardised screeners and assessment tools.

**Complex needs:** It is important that tools are developed to support early and accurate diagnosis of autism in people with complex needs, including when individuals do not use speech to communicate, intellectual disability, and other co-occurring health and developmental conditions. Furthermore, recognising that attending assessment sessions can be particularly challenging for individuals with complex needs and their families, it is important that coordinated models of assessment are developed to minimise the number and duration of sessions, while still addressing all relevant health needs (e.g., medical, allied health, dental).

**Gender diversity:** It is important to better understand the characteristics and experiences of autism among gender diverse individuals; the appropriateness of existing assessment and diagnostic criteria, tools, and practices; and where relevant to improve these.

**Rural and remote practice:** It is important that the experiences of people seeking to access assessment and diagnostic services in, and from, rural and remote locations be better understood. This includes research to identify barriers and facilitators to timely, accurate, appropriate, and affordable services, and to develop solutions to improve access where required.

**Telehealth:** While there is growing evidence for the potential benefits of telehealth, further research is needed to understand the barriers and facilitators to its use in various aspects of the assessment and diagnostic process.

**Neurodiversity-affirming practice:** The Guideline recommends that assessment and diagnostic practices should be neurodiversity-affirming. However, it is recognised that the concept is relatively new, and research is needed to achieve consistency in how neurodiversity-affirming practice is defined and to support its use and evaluation in clinical practice.

#### Co-production of assessment tools and associated research

It is important that the development of new assessment tools and models of service delivery is informed by the lived expertise of autistic people, of all ages and with different levels of support needs. Parents, partners, family and family-like people are also important partners in research to improve assessment and diagnostic services, including in relation to services for young children and people of all ages with complex needs.

#### National register of autism diagnoses

It is important that researchers have access to accurate and rich data to help inform government policy. A national register of new autism diagnoses would facilitate population-level monitoring of autism prevalence and provide a baseline for longitudinal research.

## **Future directions for practice**

Professional associations and peak bodies are encouraged to continue to endorse the Guideline and encourage their members adherence to the Recommendations. Autism CRC has produced a range of resources to support implementation of the original Guideline, including an online continuing professional development course, quick reference guides, referral and report templates, and a university resource for training future health practitioners. These resources will be updated to reflect the updated Recommendations, where relevant.

**Local clinical training.** It is important that clinicians and other professionals undertake appropriate training to ensure they have the appropriate knowledge and skills to implement the Guideline within their service. This may involve tailoring the available resources to meet the needs of their local community and type of service, and will help ensure ongoing capacity within all communities (including regional and remote communities).

**Clinical networks.** It is important to develop in-person or online clinical networks to facilitate the training of new members of an assessment team and maintain required expertise and mentoring systems. This is in recognition that peer-to-peer learning is critical to developing and maintaining high levels of clinical skills, in particular through peer observation, peer supervision and peer mentoring. One model of such a clinical network is the Western Australian Autism Diagnosticians' Forum (http://www.waadf.org.au).

## Future directions for policymakers

Government agencies and professional societies should create and maintain frameworks that incentivise and/or regulate the adherence to the full suite of Recommendations in this Guideline. For Government, a key challenge is to make assessment and diagnostic evaluation more accessible, affordable, and equitable for all Australians. The community consultation process that informed the updated Recommendations, yielded extensive evidence of shortcomings in current service provision, that have reportedly led to missed, delayed, and inaccurate diagnoses, and often poor experiences for those seeking an assessment.

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# Glossary

Term	Definition	
Acceptability	The extent to which the client perceives a particular service to be appropriate and meet their needs.	
Adaptive behaviour	Skills that help people to function in their daily lives, this includes self-care and daily living skills, skills for communicating and relating to others in everyday settings.	
Activity	The engagement in or performance of a task or action.	
Assent	The expressed approval of a person to participate in an activity, where that person is not able to give legal consent to participate. In Australia, consent for children (under 18 years of age) to receive supports is generally provided by parents.	
Augmentative and alternative communication	Communication by means other than talking, to support both comprehension (understanding) and expression. 'Augmentative' means to add to someone's speech, and 'alternative' means to be used instead of speech'.	
Autism Spectrum Disorder	Autism Spectrum Disorder (often referred to as autism or ASD) is the collective term for a group of neurodevelopmental conditions characterised by persistent difficulties in social-communication and interaction, and by restricted, repetitive patterns of behaviour, interests, or activities and/or sensory behaviours. The behavioural features that characterise autism are often present before 3 years of age, but may not become apparent until the school years or later in life. While these features can vary widely in nature and level between individuals, and in the same individual over time, there is evidence that autistic behaviours endure into adult life, though the impacts may change across the lifespan. A range of developmental, mental, and physical health conditions regularly co-occur with autism, including attention deficit hyperactivity disorder, intellectual disability, epilepsy, gastrointestinal issues, sleep disorders, language disorders, motor difficulties, and mental health problems. These co-occurring conditions, in conjunction with the core autism characteristics, can create significant barriers to a person's ability to function independently in his or her environment, with longer-term implications for educational and vocational attainment and wellbeing.	

Autism community	The community of parents, partners, and family members of autistic people, along with practitioners and other community members who seek to support autistic people.	
Autistic community	The community of autistic people.	
Autism CRC	A collaborative research organisation that is focused on autism across the lifespan, and is an independent national source of evidence for best practice. The Autism CRC funded the development of this Guideline. The Autism CRC's website is: www.autismcrc.com.au	
Clinical supervision	A professional, and often contractual, relationship in which a typically more experienced supervisor provides guidance to a practitioner on aspects of ethical and professional practice.	
Consensus-Based Recommendation	Key elements of practice that must be followed for a practitioner to deliver evidence-based supports.	
Consent	A person's agreement, based on adequate knowledge and understanding of relevant material, to participate in an activity.	
Community consultation	Refers to research activities undertaken by the Guideline Development Group to gather evidence form the autistic and autism communities to inform the development of the Guideline.	
Draft Recommendations Working Group (DRWG)	The nine members of the Guideline Development Group who led the analysis of the information collected through the research and community consultation activities to develop recommendations and make Evidence to Decision judgments. The members were Nicole Dargue, Emma Goodall, Emma Hinze, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse, and Rachelle Wicks.	
Evidence to Decision (EtD) framework	A research method that is part of the GRADE framework that guides Guideline developers to use evidence in a structured and transparent way to inform decisions in the context of Guideline Recommendations.	
Family	The individual's parents, siblings, and any extended family, including grandparents, aunts, uncles, and cousins.	
Family-like	People who are not relatives, but play a significant personal role in the client's life.	

Feasibility	The extent to which a service is able to be delivered by a practitioner in a particular context.	
Gender identity	An individual's perception and experience of their own gender. This may or may not correspond to their physiology or sex assigned at birth.	
Good Practice Points	Elements of practice that provide critical context to a given Recommendation, such as how a Recommendation should be operationalised in clinical practice, or how it is applied to a specific population or under specific circumstances.	
Grading of Recommendations Assessment, Development and Evaluation (GRADE)	GRADE is an internationally recognised research framework for assessing the certainty of evidence and strength of clinical practice recommendations.	
Guideline Development Group (GDG)	The group of people who led the research and community consultation activities upon which this guideline is based. The process for forming the GDG, membership, roles, responsibilities, and activities are described in full in the Administration and Technical Report.	
International Classification of Functioning, Disability and Health (ICF)	Commonly known as the ICF, this framework, published by the World Health Organisation, presents a biopsychosocial model for conceptualising, describing, and addressing disability in a way that considers individual, contextual, and environmental factors.	
Learning	Acquiring knowledge and skills.	
Multidisciplinary	A group of professionals from different disciplines working with a client, either independently or as a team.	
National Disability Insurance Scheme (NDIS)	The NDIS is an Australian social security system that provides funding to people with disability, their families and carers. The NDIS is jointly governed by the Australian and state and territory governments.	

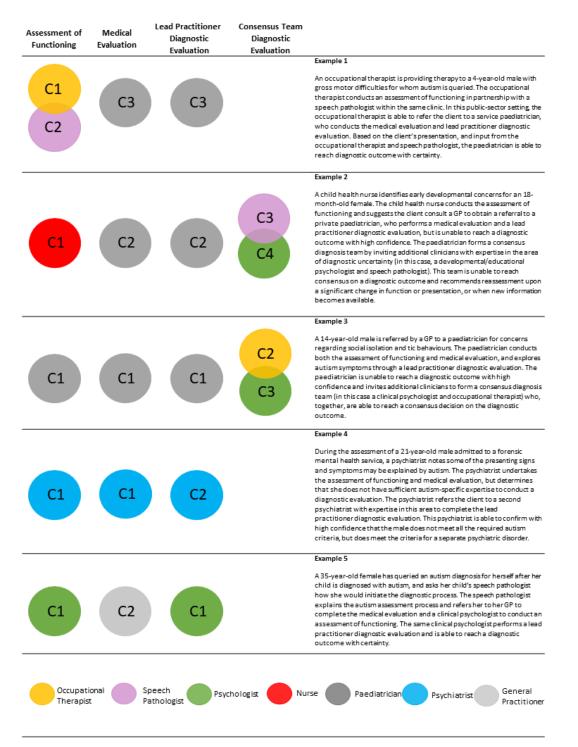
National Health and Medical Research Council (NHMRC)	The NHMRC is the main statutory authority of the Australian Government responsible for medical research. The NHMRC provides guidelines that describes the best practice approach for developing practice guidelines in Australia (called ' <i>Guidelines for</i> <i>Guidelines</i> ).	
Neurodiversity	The perspective that people experience and interact with the world in different ways. Inherent in this view is that there is no one 'normal' way of thinking, learning, and behaving, and therefore differences in behaviours should not be seen as 'deficits'. In the context of autism, a neurodiversity perspective views brain-based and behavioural differences observed in autistic people as reflecting natural human variation.	
Neurodiversity- affirming	Practices that seek to affirm the child's neurodivergent identity. In the context of autism, this term refers to providing supports that embrace each person's unique understanding of other people and the world around them, without seeking to 'cure' autism.	
Parents	Any individual with parenting or caretaker responsibilities for a child (of any age), including guardian, kinship, and foster carers.	
Participation	The involvement in life situations that a person desires and in a way that they agree to.	
Practitioners	In the context of this Guideline, practitioners primarily refers to people involved in the process of assessment and diagnosis, but also refers to the broader group of people who provide supports to autistic people and their families. The term 'practitioner' is synonymous with 'clinician' in this Guideline.	
Public consultation	Refers to the process whereby the Guideline Development Group released the Draft Guideline, gathered feedback from the autistic and autism communities, and used this feedback to refine the Guideline.	
Quality of life	An individual's perception of their own position in life, particularly in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.	

Reference Group	A group of representatives from key stakeholder organisations in Australia, who supported the community consultation process and who provided input to the guideline development process at key stages. The process for forming the Reference Group, membership, roles, responsibilities, and activities are described in full in the Administration and Technical Report.	
Research synthesis	A research project that combines the results from different studies focused on the same research question, and provides an overarching summary of those studies.	
Restrictive practices	membership, roles, responsibilities, and activities are described in full in the Administration and Technical Report. A research project that combines the results from different studies focused on the same research question, and provides an	

Service	In the content of this Guideline, service primarily refers to paid activities performed by a practitioner in the process of contributing to assessment and diagnosis.
Service provider	In the content of this Guideline, service primarily refers to an organisation that provides assessment and diagnosis services. These organisations may have a sole practitioner or many practitioners.
Telehealth	The use of telecommunications (including videoconference and internet technology) to connect a practitioner with a client at a distance for the purpose of providing a service.
Wellbeing	The combination of physical, mental, social, and emotional health, including feeling positive and well.

# Appendices

# Appendix 2.1: Examples of how flexible assessment processes described in the Guideline may work in practice.



**Figure 3. Examples of how the flexible assessment structure described in the Guideline may work in practice** Each clinician is referenced by a number (e.g. C1, C2) and is colour-coded by discipline. Refer to the recommendations in the Guideline for the information collected at each assessment stage.

# Appendix 2.2: Expertise, training, and membership for clinicians commonly involved in the Assessment Team

Practitioner	Skills and expertise	Training	Registration or membership
Paediatrician	Medical doctors who have skills and expertise in the health and medical assessment and medical treatment of neonates (birth to 4 weeks) and children (up to 25 years).	Successfully completed a medical degree accredited by the Australian Medical Council and at least 1 intern year. Successfully completed a further 3-year basic training in paediatrics and child health and 3-year Advanced Training program through the Royal Australian College of Physicians in at least one of the following paediatric specialties: Community Child Health, General Paediatrics or Paediatric Neurology.	Specialist registration with the Medical Board of Australia in the field of general paediatrics (part of the Australian Health Practitioner Regulation Agency).
Psychiatrist	Medical doctors who have skills and expertise in the assessment and treatment of people with mental illness. Child psychiatrists have expertise in children (up to 25 years) and adult psychiatrists have expertise in adults (18 years and above).	Successfully completed a medical degree accredited by the Australian Medical Council and at least 1 year of basic medical training in an accredited hospital. This is followed by successfully completing basic psychiatric training (3 years of stage 1 and 2), followed by 2 years of advanced training in adult or child and adolescent psychiatry (stage 3) in an accredited training network of the Royal Australian and New Zealand College of Psychiatrists.	Specialist registration with the Medical Board of Australia in the field of psychiatry (part of the Australian Health Practitioner Regulation Agency).

Neurologist	Medical doctors who have skills and expertise in the assessment and treatment of individuals with conditions that affect the brain, spinal cord, nerve, and muscle.	Successfully completed a medical degree accredited by the Australian Medical Council and at least 1 intern year. Successfully completed a further 3-year basic and 3-year advanced neurology training program (either adult or paediatric curriculum) through the Royal Australian College of Physicians.	Specialist registration with the Medical Board of Australia in the field of neurology (part of the Australian Health Practitioner Regulation Agency.
Psychologist	Allied health practitioners who have skills and expertise in the assessment and treatment of mental health and behavioural challenges.	Successfully completed a 4-year Australian Psychology Accreditation Council (APAC) endorsed university degree, followed by 2 years of supervised professional training to become a registered psychologist. Specialisation through an area of practice endorsement (e.g., clinical psychologist, clinical neuropsychologist or educational/developmental psychologist) typically involves at least an additional 2–3 years of formal training through either a master or doctoral program as well as 1 intern year following completion of postgraduate qualifications.	General registration, with or without a practice endorsement, with the Psychology Board of Australia (part of the Australian Health Practitioner Regulation Agency) OR General registration and practice endorsement in clinical psychology, educational/ developmental psychology or neuropsychology with the Psychology Board of Australia (part of the Australian Health Practitioner Regulation Agency).

Speech pathologist	Allied health practitioners who have skills and expertise in the assessment, diagnosis and treatment of speech, language and communication conditions, and the assessment of oral language, written language, swallowing, feeding and play.	Successfully completed a university qualification endorsed by Speech Pathology Australia. This is either a 4-year undergraduate degree or a graduate-entry master's degree.	Eligible to be a Certified Practicing member of Speech Pathology Australia.
Occupational therapist	Allied health practitioners who have skills and expertise in the assessment and treatment of personal, activity and environmental factors to assist with meaningful participation in activities and life roles across the lifespan, along with skills and expertise in sensory and motor systems.	Successfully completed a university qualification compliant with the World Federation Occupational Therapy standards. This is either a 4-year undergraduate degree or a graduate-entry master's degree.	Registration as an Occupational Therapist with the Occupational Therapy Board of Australia (part of the Australian Health Practitioner Regulation Agency).

Social worker	Allied health professionals who use a range of skills and activities to help individuals, families, groups and communities enhance their individual and collective well- being. Social work aims to help people develop their skills and ability to use their own resources and those of the community to resolve challenges.	Successfully completed a university qualification approved by the Australian Association of Social Workers (or qualifications from overseas that have been recognised as comparable). This is either a 4-year undergraduate degree or a graduate-entry master's degree.	Eligible to be a member of the Australian Association of Social Workers.
Nurse practitioner	Registered nurses with the experience and expertise to diagnose and treat people of all ages with a variety of acute or chronic health conditions.	Successfully completed university qualifications (approved by Nursing and Midwifery Board of Australia) and have 5,000 hours experience at the clinical advanced nursing practice level.	General registration and endorsed as a nurse practitioner with the Nursing and Midwifery Board of Australia (part of the Australian Health Practitioner Regulation Agency).

# Appendix 2.3: Other practitioners who may contribute information relevant to assessment and diagnosis

The following is a non-exhaustive list of practitioners whose input may be helpful to obtain a more complete clinical picture of the individual's presentation in their everyday environment or provide specialist guidance to explore alternative explanations for presenting characteristics:

- accredited practising dietitian
- audiologist
- board-certified behaviour analyst
- childcare worker
- dentist
- disability employment support person
- early intervention service provider
- gastroenterologist
- general practitioner
- geneticist
- Indigenous community health worker
- neurologist
- nurse
- occupational therapist
- ophthalmologist
- optometrist
- paediatrician
- physiotherapist
- preschool or early childhood teacher
- primary or secondary school teacher
- physiotherapist
- psychiatrist
- psychologist
- sleep and respiratory physician
- social worker
- special education teacher
- speech pathologist

# Appendix 5.1: Examples of assessments that can contribute information to decisions regarding differential diagnosis.

Assessment Focus	Types of Assessment	
Social interaction and/or communication	Receptive language (e.g., comprehension of the verbal and non-verbal communication of others)	
domain(s)	Expressive language (e.g., sound and word production, and the frequency and function of verbal and non-verbal communication)	
	Social communication (e.g., initiation of communication, social reciprocity and conversational skills)	
Repetitive patterns of behaviour,	Sensory motor assessment (e.g., presence of hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment)	
interests, or activities domain	Behavioural assessment (e.g., challenging behaviour which falls outside the range of expected age-appropriate behaviour)	
	Mental health assessment (e.g., rituals, obsessive compulsive behaviours, tics, anxiety)	
	Neurological assessment (e.g., epilepsy, tics)	
Possible differential or co-	Cognitive and/or neurodevelopmental assessment (e.g., intelligence, learning capability, visual perception, memory, executive functioning)	
occurring diagnosis	Developmental assessment (e.g., ability to meet expected developmental milestones related to motor and social-emotional domains)	
	Hearing assessment (e.g., screening test or full auditory evaluation)	
	Mental health assessment (e.g., psychiatric screening or diagnostic tool to identify the presence of a range of mental health signs, symptoms or conditions)	
	Selective metabolic and/or genetic screen (e.g., chromosomal microarray, amino acid chromatography, thyroid function)	
	Neurological testing (e.g., electroencephalogram, computed tomography scan, magnetic resonance imaging)	
	Vision assessment (e.g., screening test, sight test or full ophthalmologist evaluation)	

# **Our values**



## Inclusion

Valuing lived experience

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## **Innovation** Solutions for long term challenges



**Evidence** Truth in practice



# Independence



Cooperation Capturing opportunities together



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