



# National Guideline

For the assessment and diagnosis  
of autism in Australia

PUBLISHED 2018 | UPDATED 2023



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**ISBN:** 978-1-922365-52-1

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**Cover artwork:** Dr Emma Goodall

## Citing this Guideline

This is an updated version of the original Guideline published in 2018.

**Citation for updated Guideline:** Goodall, E., Dargue, N., Hinze, E., Sulek, R., Varcin, K., Waddington, H., Whitehouse, A. J. O., Wicks, R., Allen, G., Best, J., Eapen, V. Evans, K., Hiremath, M, Foster, W., Lawson, W., Toby, S., & Trembath, D. (2023). *National Guideline for the assessment and diagnosis of autism in Australia*. Brisbane: Autism CRC.

**Citation for original Guideline:** Whitehouse, A.J.O., Evans, K., Eapen, V., Wray, J. (2018). *A National Guideline for the assessment and diagnosis of Autism Spectrum Disorders in Australia*. Brisbane: Autism CRC.

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## Publication Approval



**Australian Government**

**National Health and Medical Research Council**

The guideline recommendations on pages 56-117 of this document were approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) on 8 December 2023 under section 14A of the *National Health and Medical Research Council Act 1992*. In approving the guideline recommendations, NHMRC considers that they meet the NHMRC standard for clinical practice guidelines. This approval is valid for a period of five years.

NHMRC is satisfied that the guideline recommendations are systematically derived, based on the identification and synthesis of the best available scientific evidence, and developed for health professionals practising in an Australian health care setting.

This publication reflects the views of the authors and not necessarily the views of the Australian Government.

# Acknowledgements

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The Guideline Development Group warmly acknowledges the following people who have contributed to the development of the Guideline.

## Autistic people, families, and community

We warmly acknowledge and thank all members of the autistic and autism communities who have so generously shared their experiences, insights, views, and expertise to inform the original Guideline and this update. This includes participation in the original studies included in the systematic reviews undertaken as part of the development and update, participating in the community consultation activities, and providing feedback on draft versions of the Guideline.

## 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.

## Research support

We warmly acknowledge and thank Veronica Frewer (Griffith University) who provided project coordination support and contributed to the research activities, along with Katie Brooker (University of Queensland), Briohny Dempsey (Telethon Kids Institute), Amy Giesberts (University of Queensland), and Libby Groves (Griffith University) who supported the research activities. We thank Dr Bahareh Afsharnejad (Curtin University) and Prof David Amor (University of Melbourne; Murdoch Children's Research Institute; The Royal Children's Hospital) who each completed Appraisal of Guidelines Research & Evaluation (AGREE-II) ratings for the draft updated Guideline.

## 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

We warmly acknowledge and thank the following people who provided additional assistance in updating the Guideline. Justina Sparks (Telethon Kids Institute) and Felicity Rose (Telethon Kids Institute) provided expert input regarding current and planned Guideline implementation activities. The following people at Autism CRC contributed to sharing information with the community about the Guideline development process and preparing the documents (graphic design, copyediting): Jason Kotzur, Darcy Maguire, Braeden Monnier, and Sally Vidler. Quinn Venz illustrated the artwork, designed by Will Foster (Guideline Development Group member), that features in the Guideline.

## Artwork



We thank Dr Emma Goodall for providing the cover art for the National Guideline.

The artwork is titled *The Disconnect in the Infinity of Neurodiversity*. Artist Dr Emma Goodall describes the artwork below.

Hidden under the layers of the  $\frac{3}{4}$  of an infinity symbol are a normal distribution curve, a brain and branches seeking connection from a brain/person to an anchor. The  $\frac{3}{4}$  infinity symbol also more explicitly shows the variety within the spectrum but the gaps in knowledge and connections.

# Guideline funding

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The Guideline was developed (2018) by Autism CRC with support from the National Disability Insurance Agency, including funding to support the coordination of the project (by Dr Kiah Evans), for the public consultation activities and for an honorarium to the Steering Committee members. Andrew Whitehouse, Valsamma Eapen, Margot Prior and John Wray received no personal financial or other remuneration for their involvement in this project.

The Guideline was updated (2023) and will be disseminated and implemented with funding from Autism CRC. David Trembath (Griffith University; Telethon Kids Institute) and Emma Goodall (Griffith University) were appointed Co-chairs of the Guideline Development Group, and Griffith University and Telethon Kids Institute received funding from Autism CRC to support this work. David's contributions were in-kind, with funding used to employ Emma Goodall and research fellows/assistants to support the work, to support community consultation activities, and to pay honoraria to the Guideline Development Group members.

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# Executive summary

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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 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 the Recommendations 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 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 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**



# Plain language summary

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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-affirming, 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. The 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 commence with a Lead Practitioner Diagnostic Evaluation or a Consensus Team Diagnostic Evaluation, depending on which is likely result in a more timely and accurate 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



# List of Recommendations

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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 (EtD) 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

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## 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 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

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### 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

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### 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

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## Recommendation 6

### Consensus-Based Recommendation

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

Grade of Recommendation: Strong

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## Recommendation 7

### Consensus-Based Recommendation

**Respecting First Nations Peoples:** Services should be culturally-affirming 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

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## 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

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## 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 who they are, where they live, or their resources.

Grade of Recommendation: Strong

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## 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.

Grade of Recommendation: Strong



## Section 2: Foundations of assessment

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### 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

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#### Recommendation 13

##### Consensus-Based Recommendation

Practitioners should commence with a Lead Practitioner Diagnostic Evaluation or Consensus Team Diagnostic Evaluation, depending on which is more likely to result in a more timely and accurate evaluation.

Grade of Recommendation: Strong

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### 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.

Grade of Recommendation: Strong

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## Recommendation 16

### Consensus-Based Recommendation

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

Grade of Recommendation: Strong

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## 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

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## 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: Conditional

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## 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.

Grade of Recommendation: Strong

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## Recommendation 21

### Consensus-Based Recommendation

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

Grade of Recommendation: Strong

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## 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

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## How should information be shared?

## Recommendation 23

### Consensus-Based Recommendation

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

Grade of Recommendation: Strong

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## 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.

Grade of Recommendation: Strong

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## Recommendation 26

### Consensus-Based Recommendation

Practitioners should share information with other relevant 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

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## 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

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## 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

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## 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

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## 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

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## Recommendation 31

### Consensus-Based Recommendation

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

Grade of Recommendation: Strong

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## Recommendation 32

### Consensus-Based Recommendation

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

Grade of Recommendation: Strong

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## 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

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## 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

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## 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 client 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

## Section 3: Making a referral for assessment

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### 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

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

#### Recommendation 38

##### Consensus-Based Recommendation

Primary healthcare providers should make referrals within the assessment and diagnostic process, where appropriate.

Grade of Recommendation: Strong

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### 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.

Grade of Recommendation: Strong

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### Recommendation 41

#### 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



## Section 4: Comprehensive Needs Assessment

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### 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

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#### Recommendation 43

##### Consensus-Based Recommendation

An Assessment of Functioning should be conducted, if relevant and appropriate, 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

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### Who should conduct an Assessment of Functioning?

#### Recommendation 44

##### Consensus-Based Recommendation

An Assessment of Functioning should be conducted by one or more health practitioners with specified medical, nursing, or allied health 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.

Grade of Recommendation: Strong

## 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

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### 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

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## 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

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## 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.

Grade of Recommendation: Strong

## Recommendation 50

### Consensus-Based Recommendation

A medical practitioner may collaborate in collecting information for the Medical Evaluation with 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.

Grade of Recommendation: Strong

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## 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 individual characteristics and support needs, that can inform differential diagnosis and recommendations for support options.

Grade of Recommendation: Strong

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## 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

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## 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

## Section 5: Diagnostic Evaluation

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### 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

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### 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.*

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#### 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.*

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## 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

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## 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

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## 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

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## 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

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## 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

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## 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

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

**Grade of Recommendation:** Strong

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### Recommendation 66

#### Consensus-Based Recommendation

Practitioners should document recommendations, discuss these with the client, and refer for further assessment and/or supports, where appropriate.

**Grade of Recommendation:** Strong



# Introduction





# Introduction

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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, 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 within the 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, 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 practitioners 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:

- Describes a rigorous framework for accurately determining whether an individual meets the criteria for a clinical diagnosis of autism.
- Outlines a comprehensive approach to identify related support needs.
- 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.
- 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.
- 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.

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

Aspect	In scope	Out of scope
<b>Recipients of services</b>	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.
<b>Focus of assessment</b>	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.
<b>Outcomes of assessment</b>	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.

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.
- 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:

- Individuals who have characteristics that may be explained by an 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.
- 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 this 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.
- 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.
- 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



# Guideline development process

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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 Co-chairs 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.



**Table 2. Members of the Guideline Development Group.**



**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**

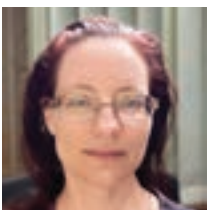
Dr Kiah Evans coordinated the development of the first Guideline from 2016 to 2018. She has held leadership roles in multiple research projects over the past six years that have focused on exploring the perspectives of autistic adults, caregivers, clinicians and other key stakeholders in relation to 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, adjunct researcher at the University of Southern Queensland and senior industry researcher with Griffith University. She is the Director of the South Australian Government Office for Autism. Emma 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, 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. 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 Autism CRC's National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia.

David was 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

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 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.

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

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)	Thea Dunkley	Assistant Director, Disability
		Jess Styles	Director, Programs

Stakeholder group	Organisation	Representative	Position
<b>Culturally and linguistically diverse communities</b>	Australian Multicultural Health Collaborative	Daniel Coase	Senior Advisor
<b>Focusing on health</b>	Neurodevelopmental and Behavioural Paediatrics Society of Australasia	John Wray	Member
<b>Focusing on health</b>	Australian College of Nurse Practitioners	Stephanie Dowden	Member
<b>Focusing on health</b>	Royal Australian College of General Practitioners	Alison Palmer	Member
<b>Focusing on health</b>	Royal Australian and New Zealand College of Psychiatrists	Matthew Sellen	Member, RANZCP Section of Psychiatry of Intellectual and Developmental Disabilities
<b>Focusing on social-communication functioning</b>	Speech Pathology Australia	Amy Fitzpatrick	Senior Advisor, Disability
<b>Focusing on physical functioning</b>	Australian Physiotherapy Association	Kristy Nicola	APA National Paediatric Group – Deputy Chair
<b>Focusing on cognitive functioning and mental health</b>	Australian Psychological Society	Catriona Davis-McCabe	APS President
<b>Focusing on sensory functioning and occupations</b>	Occupational Therapy Australia	Gaynor Gray	Divisional Manager (QLD), Occupational Therapy Australia
<b>Focusing on rural health</b>	National Rural Health Alliance	Susanne Tegen	Chief Executive

Stakeholder group	Organisation	Representative	Position
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 Division

## 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 and community consultation underpinning the Guideline.**

Section	Question
<b>Guiding principles</b>	What guiding principles should be followed in the assessment and diagnosis of autism?
<b>Foundations of Assessment</b>	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?
<b>Making a referral for assessment</b>	When should a referral for autism assessment be initiated?
	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?

Section	Question
<b>Comprehensive Needs Assessment</b>	When should an Assessment of Functioning be conducted?
	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?
<b>Diagnostic Evaluation</b>	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 a systematic review 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.
- 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:

- All text from the original Guideline was transferred to a Microsoft Excel spreadsheet and organised according to the original Guideline questions.
- This text was re-organised according to the updated Guideline questions.
- The Recommendations and accompanying text related to each of the updated Guideline questions was reviewed, individually and as a group.
- 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.
- 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 Co-chair 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 (Supporting Evidence, Administration and Technical Report, and Easy Read summary) for public consultation, which opened on 17<sup>th</sup> April 2023 and closed on 29<sup>th</sup> May 2023 (a 6-week period).

### Ahead of public consultation

The public consultation on the draft updated Guideline complied with Section 14A 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 update to reflect the upcoming consultation period and the invitation to participate.
- Autism CRC announced the upcoming public consultation period, via an email distributed to people who had registered specifically for updates on the Guideline, as well as to people whose details were listed in 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.
- An email was sent to 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. These officers were then directly emailed the draft updated Guideline, when it was released.

### During public consultation

During public consultation, Autism CRC:

- Updated its website to include:
  - Direct links to the draft updated Guideline, Supporting Evidence, Administration and Technical Report, and an Easy Read summary of the Guiding Principles.
  - A link to participate in an online feedback survey.
- Announced the opening and closing of the public consultation period via email and social media.
- Sent reminders inviting participation throughout the public consultation period.

### Feedback survey

Public consultation feedback was collected via a custom online survey, developed by the GDG and delivered via REDCap (Griffith University). The survey link directed all participants to a Participant Information Statement and Consent form. For consenting participants, they were then given the opportunity to provide feedback on the draft updated Guideline by (a) providing feedback on the Guideline sections, (b) providing feedback on specific Recommendations and Good Practice Points, and (c) providing any other general feedback about the draft updated Guideline. Participants were able to choose the number of questions they answered. Furthermore, participants were able to choose whether to provide feedback as an individual, or on behalf of an organisation. Where feedback was provided on behalf of an individual, participants were able to choose whether or not they would like their feedback to be published anonymously in the final updated Guideline. Where feedback was provided on behalf of an

organisation, a copy of the survey was available for download to assist those completing the survey to compile feedback within their organisation.

The feedback survey was accessed 821 times during the consultation period with 808 individuals providing informed consent. Of the 808 individuals providing informed consent, 358 provided feedback on the draft updated Guideline. Of those who provided feedback (and hence, the submission was considered by the GDG), 339 participants indicated that they were providing feedback as an individual and 19 participants indicated that they were providing feedback on behalf of an organisation.

### **Independent review: AGREE-II**

As per NHMRC Guidelines for Guidelines, the GDG arranged for the draft updated Guideline to be reviewed by two independent researchers with experience with the Appraisal of Guidelines for Research & Evaluation Instrument (AGREE-II) checklist: Dr Bahareh Afsharnejad (Curtin University) and Professor David Amor (University of Melbourne; Murdoch Children's Research Institute; The Royal Children's Hospital).

### **Independent review: NHMRC**

The NHMRC organised for five experts across four countries (Australia, New Zealand, United Kingdom, United States) to independently review the draft updated Guideline using a standard form supplied by NHMRC. These reviewers focused on the extent to which the draft updated Guideline aligned with its identified scope and clinical questions, whether the Recommendations adequately consider the risks and potential harms of clinical practice, and whether there are relevant international guidelines on the same topic that conflict with the Recommendations made. The NHMRC also arranged for methodological review of the draft updated Guideline, focusing on the extent to which the draft updated Guideline complied with the NHMRC Standards for Guidelines.

### **Health Department review**

The Office of the Director General, Chief Executive or Secretary of each State, Territory, and Commonwealth Health Department were invited to provide feedback on the draft updated Guideline, in a form of their choosing (e.g., letter).

## Step 7: Analysing feedback and revisions

All feedback received through public consultation and independent review was considered and used to inform revisions to the updated Guideline where relevant, in a systematic manner.

### Feedback from public consultation

The DRWG, which for this process included members of the GDG (Emma Goodall, Emma Hinze, Rhylee Sulek, David Trembath, Kandice Varcin, Andrew Whitehouse, Rachelle Wicks) with research support from Amy Giesberts, reviewed each piece of feedback received through the online feedback survey. There was a structured process for responding to each piece of feedback:

- One member of the DRWG exported all of the feedback from the survey portal into a spreadsheet. All feedback in the spreadsheet was de-identified (i.e., there was no demographic or organisational information attached to the feedback). Feedback on the (a) sections of the draft updated Guideline, and (b) Recommendations were collated in one tab, for the GDG to review and respond. General 'other' feedback on the draft updated Guideline was collated in a separate tab for the GDG to review but there was no formal, published response to this feedback, as specified to participants in the online survey.
- Feedback was then read by a member of the DRWG, and an initial response and/or proposed change to the Guideline was drafted, where possible. At this point, feedback was categorised as either (a) requiring no change to the Guideline, (b) requiring a possible change to the Guideline, or (c) requiring broader consultation with the DRWG to address the feedback.
- A second member of the DRWG then reviewed the feedback and the initial response and/or proposed change and noted that they either (a) agreed with the initial DRWG member's response, or (b) they proposed an amendment to the initial response.
- For feedback requiring broader consultation with the DRWG, the feedback was collated and brought to the full DRWG for discussion and a group consensus decision was made regarding a response and/or change to the Guideline.
- At least one Co-chair then reviewed every piece of feedback and either endorsed the proposed response without changes or endorsed the proposed response with changes.
- Final, agreed upon changes were incorporated into the Guideline document by DRWG members, and all corresponding points in the Administration and Technical Report, Supporting Evidence, and Easy Read summary of the Guiding Principles.
- The DRWG and the broader GDG were provided the opportunity to review every change proposed in all documents.
- The DRWG members then compiled all feedback and the final responses (including why or why not a change was made to the Guideline) as well as the nature and location of any change that had been made. The feedback tables are provided in the Public Consultation Summary, published with the updated Guideline.

### **Feedback from independent review: AGREE-II expert reviews**

All feedback was considered by members of the DRWG and changes made where relevant (e.g., a new section further explaining the applicability of the Recommendations when working with all clients, including those with complex needs, was added to the introduction of the Guideline).

### **Feedback from independent review: NHMRC expert reviews**

All feedback was considered by members of the DRWG and changes made where relevant. A copy of the reviewer feedback and the GDG's responses is provided in the Public Consultation Summary.

### **Feedback from Health Departments reviews**

All feedback was considered by members of the DRWG and changes made where relevant. A copy of the reviewer feedback and the GDG's responses is provided in the Public Consultation Summary.

### **Guideline Development Group review of feedback and changes**

All GDG members were provided with a penultimate draft of the updated Guideline with changes highlighted and accompanying comments that explained the changes made. The GDG members had access to the complete set of feedback from the Public Consultation and independent review process. Once satisfied, each member of the GDG confirmed their endorsement of the documents via email to the GDG Co-chairs.

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

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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-affirming 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 updated 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



# Reading the Guideline

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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. 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 concepts 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.’ Adopting a neurodiversity-affirming approach to practice in no way diminishes acknowledgement of the profound disability experienced by many autistic people, including those with co-occurring intellectual disability and/or complex communication needs. Rather, a neurodiversity-affirming approach values and respects each person for who they are, and focuses on identifying and addressing their support needs.

## Accounting for different support needs

The Recommendations in the Guideline are relevant to clients with the full range of support needs, including individuals who experience profound disability. Adopting this approach helps to support consistency in key elements of clinical practice while maintaining the flexibility required to tailor the assessment and diagnostic process for individual clients. Indeed, the need to consider each client’s characteristics, functioning, and context, including strengths and support needs is explicit in the Recommendations. Practitioners are advised to consider the Good Practice Points that accompany each Recommendation, which highlight important considerations in relation to support needs, such as accommodating and supporting the use of augmentative and alternative communication (AAC) systems by people with complex communication needs.

## 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 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. Capitalisation (i.e., Recommendation/s) is used when referring to Recommendations in the Guideline, while lower case (i.e., recommendations) is used to when referring to recommendation/s in the general sense.

## 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**



# Acknowledging and respecting Aboriginal and Torres Strait Islander Peoples

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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, affirming, 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.



# Section 1: **Guiding principles**



# Section 1:

## Guiding Principles

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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 and update process 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 appropriate knowledge and skills, and work in ways that are culturally-affirming and respectful of Aboriginal and Torres Strait Islander Peoples and other culturally diverse groups within the community. They should work and communicate in ways that are neurodiversity-affirming and thus value each person for whom 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 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.

- 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-affirming:** Practitioners should acknowledge and respect the values, knowledge, preferences, and cultural perspectives of the client; adopt culturally-affirming 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-affirming 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 who they are, where they live, or their resources.

- 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.

- Grade of Recommendation: Strong



# Section 2: Foundations of assessment



# Section 2:

## Foundations of assessment

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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 assessment

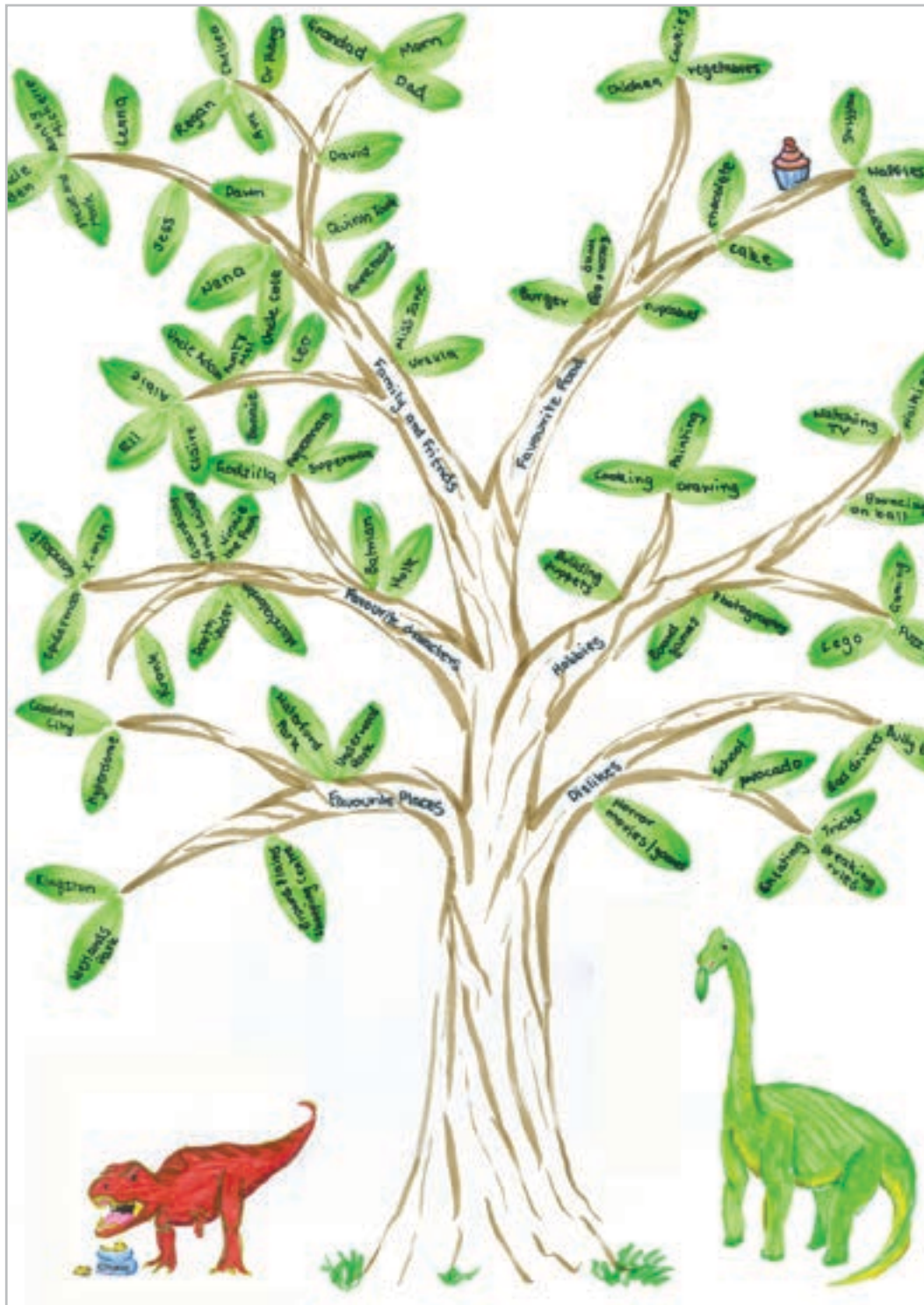
In its most literal form, the ultimate purpose of assessment that considers a possible diagnosis of autism is to determine if the client meets the diagnostic criteria for autism, and/or other conditions. However, it is essential that assessments achieve a much broader aim of understanding the client and their context. There are many 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 Organization, 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 their explicit mentioning is relevant.

The following two artworks illustrate the purpose of assessment from two different viewpoints.

The first artwork, designed by Will Foster (Member, Guideline Development Group) and illustrated by Quinn Venz, shows the importance of ensuring that the client is at the centre of all aspects of the assessment and diagnostic process, with each leaf representing an important aspect of life. Using a tree as a symbolic framework, this personal reflection demonstrates how individuals with complex communication needs can utilise various symbols, pictures, and communication aids to express their

preferences, strengths, challenges, and personal narratives. This visual and interactive method of information gathering not only organises the information but also promotes a person-centred approach to communication, enabling individuals to engage meaningfully and participate actively in assessment processes. Just as branches and leaves on a tree represent different aspects, this approach allows individuals to communicate in a more accessible and meaningful way, fostering a holistic understanding of their needs.



**Figure 2.1.** Design by Will Foster (Member, Guideline Development Group), illustration by Quinn Venz.



In the second artwork, Samarra Toby (Member, Guideline Development Group) shares a personal reflection. Samarra writes:

“As a First Nations doctor and Mother to a child with autism we view and see our children in a way of their spirit and being, they are not defined by a diagnosis. Our Gangulu and South Sea cultural connections acknowledge that the health and broader life ecosystems transition through unpredictable yet recurring cycles of growth and creation.

The Gangulu have an evolving knowledge network acquired by ancestors over hundreds of thousands of years – time immemorial through direct contact with the environment, land and waters. This knowledge is specific to our homelands – Gangulu country – and includes the relationships between plants, animals, traditional medicines, natural phenomena, landscapes and timing of events that are used for lifeways.

The Gangulu people, our homeland, our spirit dreaming and the environment are an interconnected framework that envelops our children in care and centredness – we are one organism. Intergenerational knowledge and connection to our homelands, spiritual, physical, emotional and community wellbeing helps us to identify and redefine challenges for our children, with interwoven solutions within a cultural framework of healing and acceptance of ‘child spirit seeing’ and ‘child seeing dreaming.’ The Gangulu consider our children to be the centre of our spiritual and cultural ecosystem and all things focus on their spiritual, physical, psychosocial and dreaming wellbeing.”



Figure 2.2. Artwork by Samarra Toby (Member, Guideline Development Group).

# 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 in Figure 2.3, 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.

## Making a referral

The process begins with an individual seeking advice from a health practitioner, who then makes referrals within the assessment and diagnostic process. The first contact may be initiated by the individual themselves, a family member (e.g., parent, caregivers), or another person (e.g., a practitioner already working with a client who observes autism characteristics). The first formal referral within the assessment and diagnostic pathway typically comes 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:

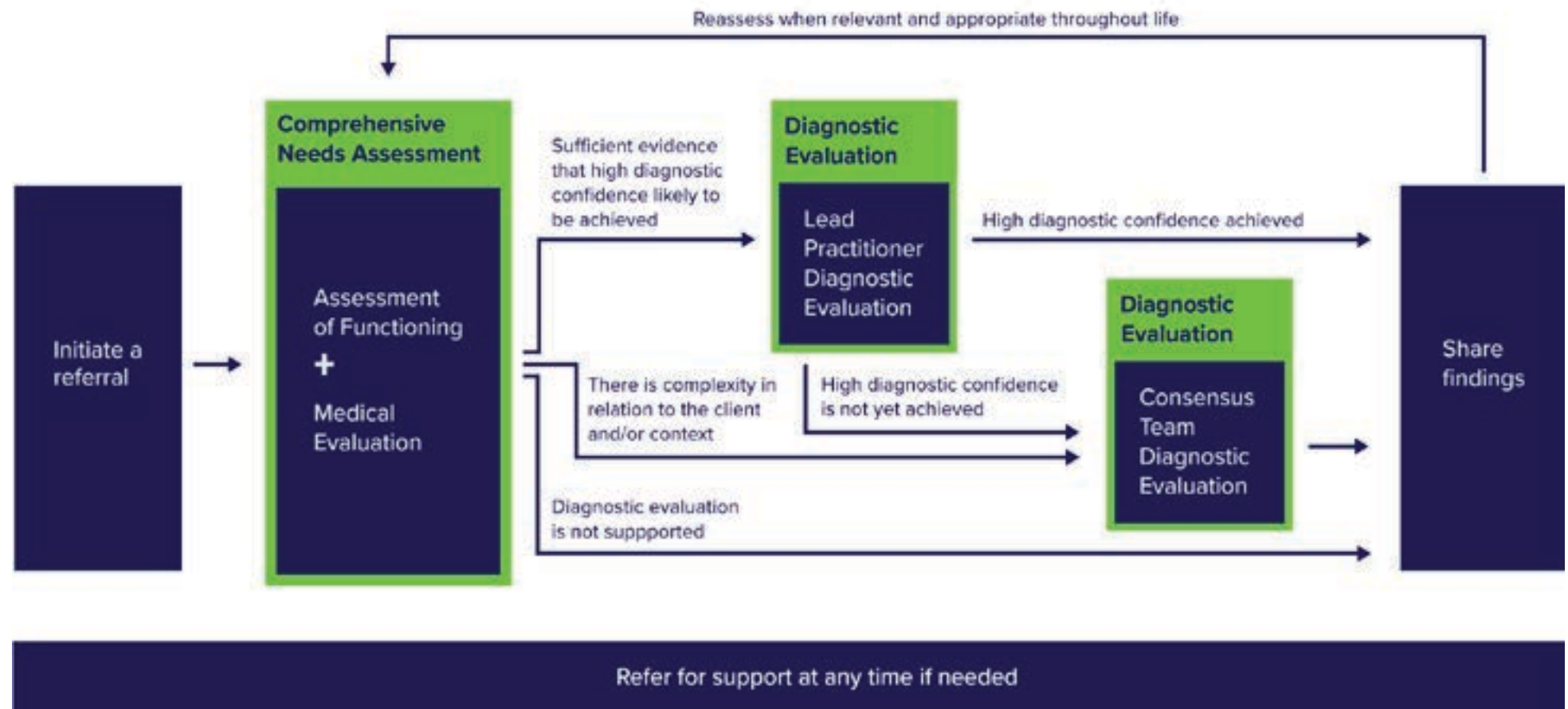
- **Assessment of Functioning:** The Assessment of Functioning focuses on understanding the client's characteristics, functioning, context, strengths and support needs. The assessment includes taking a case history and typically involves the use of a variety of tools such as an interview, observations, and assessment tools designed to examine functioning in a range of relevant ICF domains (World Health Organization, 2001). 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

**Figure 2.3.** Process for assessment and diagnosis of autism in Australia.



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).

In conducting a Diagnostic Evaluation, the focus is on differential diagnosis, in which all possible explanations for the client's characteristics, strengths, and support needs are explored. 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 2.3, 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 it is apparent that a client has a complex history or clinical presentation (e.g., subtle characteristics, indications that multiple diagnoses may be relevant) or when a Lead Practitioner Diagnostic Evaluation is unavailable or unable to lead to a diagnostic decision with high confidence. 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. As also indicated in Figure 2.3, a Comprehensive Needs Assessment may not indicate the need for a Diagnostic Evaluation, in which case findings are shared and referral for supports is considered.

## 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 Organization, 2019). These practitioners have specified medical, nursing, and/or allied health qualifications that are directly relevant to addressing these aims.

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	✓	✓	Specified <sup>b</sup>	✓ <sup>d</sup>
Psychologist	✓	×	Specified <sup>c</sup>	✓ <sup>d</sup>
Registered nurse	Specified <sup>a</sup>	Specified <sup>a</sup> (collaborate)	×	×
Occupational therapist	✓	×	×	✓ <sup>d</sup>
Social worker	✓	×	×	×
Speech pathologist	✓	×	×	✓ <sup>d</sup>

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

<sup>a</sup> To conduct an Assessment of Functioning or collaborate on Medical Evaluation, it is recommended that they be a nurse practitioner, mental health nurse practitioner, or a registered nurse with relevant experience as a clinical nurse specialist/consultant.

<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 an area of practice endorsement in clinical psychology, clinical neuropsychology, and/or educational/developmental psychology.

<sup>d</sup> The Consensus Team Diagnostic Evaluation should include at least one member who meets the specified criteria for conducting a Lead Practitioner Diagnostic Evaluation.

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 and functioning 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 identified.

► 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 commence with a Lead Practitioner Diagnostic Evaluation or Consensus Team Diagnostic Evaluation, depending on which is more likely to result in a more timely and accurate evaluation.

► Grade of Recommendation: Strong

#### Good Practice Points:

- 13.1 A Lead Practitioner Diagnostic Evaluation should be considered when there is sufficient evidence on which a diagnosis of autism and/or other conditions can be confirmed or ruled out with high confidence.
- 13.2 A Consensus Team Diagnostic Evaluation should be considered when it is apparent that a client has a complex history or clinical presentation (e.g., subtle characteristics, indications that multiple diagnoses may be relevant) or when a Lead Practitioner Diagnostic Evaluation is unavailable or does not result in a diagnostic decision with high confidence.
- 13.3 Practitioners should be aware that utilising the Lead Practitioner Diagnostic Evaluation, where appropriate, has the potential to improve clients' access to a more timely and affordable Diagnostic Evaluation.



# 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

### Good Practice Points:

- 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-affirming practices when working with Aboriginal and Torres Strait Islander Peoples and other culturally diverse groups within the community, including different cultural frameworks of health and development.
  - 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 and 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.
  - How intersectionality of personal and contextual factors may influence a client's presentation, strengths, and support needs, such as being a member of the LGBTQI+ community, being culturally and linguistically diverse, and the presence of other psychosocial factors.
  - 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.

## 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.

► Grade of Recommendation: Strong

### Good Practice Points:

- 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., 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.



## Recommendation 16

### Consensus-Based Recommendation

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

► Grade of Recommendation: Strong

#### Good Practice Points:

- 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-affirming practices, including when working with Aboriginal and Torres Strait Islander Peoples, and other culturally diverse groups within the community.
  - 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, nursing, 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 is emerging regarding 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

### Good Practice Points

- 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.

## 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: Conditional

### Good Practice Points

- 18.1 Where possible, practitioners should provide the client with the opportunity for in-person 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 sections of the 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

#### Good Practice Points:

- 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 should be supportive of clients 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 an 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 consult with all relevant stakeholders to collect information that relates to the referral and/or assessment.

► Grade of Recommendation: Strong

### Good Practice Points:

- 21.1 Practitioners should collect and consider information from all relevant practitioners and other stakeholders (e.g., family members, teachers, support workers), 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

### Good Practice Points

- 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 the 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 that practitioners do 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 the client's reason for seeking 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 presented visually, in tables, using text), functioning (e.g., literacy), and preferences (e.g., summarised versus detailed, in-person 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

### Good Practice Points

- 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

### Good Practice Points

- 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 including those offered by autistic people and others with lived experience of autism (e.g., parents, caregivers, siblings) 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-affirming, 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

#### Good Practice Points:

- 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.

## 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

#### 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

#### Good Practice Points

- 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.

## Recommendation 31

### Consensus-Based Recommendation

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

► Grade of Recommendation: Strong

### Good Practice Points

- 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.
  - Being aware of any physical (e.g., vision, hearing) or mental health needs the client may have and making appropriate accommodations.
  - 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.
- 31.7 Practitioners should be aware of obligations and mechanisms to report safety concerns, such as via the National Disability Insurance Scheme Quality and Safeguards Commission and the National Disability Abuse and Neglect Hotline.

## Recommendation 32

### Consensus-Based Recommendation

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

► Grade of Recommendation: Strong

#### Good Practice Points:

- 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 diverse and atypical presentations of mental health conditions in autistic individuals, particularly co-occurring 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 services that are available to them (e.g., Lifeline, Carer Gateway, autism-specific organisations).

## 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

### Good Practice Points

- 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.



## 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

### 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, 2009).
- 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 client 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

### Good Practice Points

- 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 make the client feel safe, secure, and supported.
- 36.5 Practitioners should work in ways that help the client develop their sense of self-worth and confidence in their self-identity.

# Section 3:

## Making a referral for assessment



# Section 3:

## Making a referral for assessment

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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

#### Good Practice Points

- 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?

As noted above, a range of people can contribute to identifying characteristics of autism and encouraging a person to contact a health practitioner. Individuals can also self-refer for an assessment, such as via a general practitioner or directly to an allied health practitioner, within Medicare constraints. Given this Guideline focuses on practitioners, Recommendations below focus on their role in supporting clients in the assessment and diagnostic process.

Primary healthcare providers are practitioners 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 also include registered nurses, nurse practitioners, allied health professionals, midwives, pharmacists, dentists, and Aboriginal health workers.

### Recommendation 38

#### Consensus-Based Recommendation

Primary healthcare providers should make referrals within the assessment and diagnostic process, where appropriate.

► Grade of Recommendation: Strong

#### Good Practice Points

- 38.1 Practitioners should be aware that any person may self-refer in relation to seeking an autism assessment.
- 38.2 Practitioners should make referrals within the assessment and diagnostic process where appropriate, which includes ensuring a need is identified, referral is desired by the client, making the referral is within the practitioners scope of practice, and Medicare rules allow.
- 38.3 Practitioners should make referrals within the assessment and diagnostic process where required, such as seeking the opinion of at least one other practitioner when undertaking a Lead Practitioner Diagnostic Evaluation or referring for an aspect of assessment (e.g., Medical Evaluation) that is outside the practitioners scope of practice.

## 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

#### Good Practice Points:

- 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 of 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 relevant case history and 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.

## Recommendation 41

### 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

### Good Practice Points

- 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



# Section 4:

## Comprehensive Needs Assessment

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The Comprehensive Needs Assessment comprises an Assessment of Functioning and a Medical Evaluation. The Assessment of Functioning is usually completed by one or more health practitioners with specified medical, nursing, or allied health qualifications and expertise in assessing a client's functional capacity and needs in everyday activities. The Medical Evaluation is completed by a medical practitioner, and can include collaboration with a nurse practitioner, mental health nurse practitioner, or a registered nurse with relevant experience as a clinical nurse specialist/consultant. 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

#### Good Practice Points:

- 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.

### 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

#### Good Practice Points

- 43.1 Further assessment can be conducted as required by practitioners 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?

An Assessment of Functioning should be conducted by one or more health practitioners with specified medical, nursing, or allied health 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 one or more health practitioners with specified medical, nursing, or allied health 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.*

#### Good Practice Points:

- 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, mental health nurse practitioner, or 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 an area of practice endorsement in clinical psychology, clinical neuropsychology, and/or educational/developmental psychology with the Psychology Board of Australia.
  - Social worker who is eligible to be a member of the Australian Association of Social Workers, and may hold additional credentials (e.g., mental health, disability).
  - 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 Organization, 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 Organization, 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, Out of Home Care, 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 co-occurring condition and/or differential diagnosis, including cognitive functioning.
- 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 consider all plausible explanations for a client's behaviour when establishing their strengths and support needs, as well as considering diagnostic characteristics. For example:
- A client may be engaging in behaviours that harm themselves, others, and/or property. Practitioners should consider the nature and possible functions of behaviour (e.g., what the client may be communicating through the behaviour), as well as individual and environmental factors that influence and maintain the behaviour. Consideration should also be given to aspects of the client's health and wellbeing, including medical conditions, that may cause and/or contribute to the behaviour (e.g., a child hitting their head due to earache, unrecognised constipation).
  - A client may avoid demands and expectations in everyday life to an extreme extent. Rather than being viewed as the client being oppositional or defiant, practitioners should consider whether the behaviours are instead driven by an anxiety-based need to be in control. *Pathological (or extreme) demand avoidance* refers to a set of characteristics that can co-occur with autism and is recognised as a behavioural profile within autism. This profile is also referred to as *persistent drive for autonomy*, emphasising the function the behaviours serve.
- 45.9 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

#### Good Practice Points:

- 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

#### Good Practice Points:

- 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 collaborate in collecting information for the Medical Evaluation with 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.

► Grade of Recommendation: Strong

#### Good Practice Points

50.1 In addition to holding the relevant qualification, nurses and 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 client's behavioural presentation, and to contribute to the identification of support needs.

## 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

### Good Practice Points:

51.1 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.
  - Mental health assessment.
- Other relevant history including social history and family history.

51.2 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 conduct 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

#### Good Practice Points:

- 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



# Section 5:

## Diagnostic Evaluation

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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

##### Good Practice Points:

- 54.1 Practitioners should explain the potential benefits of undertaking a Diagnostic Evaluation, irrespective of whether the client receives an autism diagnosis or not. These may vary for individual clients, but can include:
- The client gaining a better understanding of themselves, 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 incorporates 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 at least one member meeting the specified criteria for conducting a Lead Practitioner Diagnostic Evaluation. The choices regarding who is included should be 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.*

#### Good Practice Points:

- 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 an area of practice endorsement in clinical psychology, clinical neuropsychology, and/or educational/developmental psychology with the Psychology Board of Australia.
- 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 an area of practice endorsement in clinical psychology, clinical neuropsychology, and/or educational/developmental psychology with the Psychology Board of Australia.
  - Speech pathologist who is eligible to be a certified practicing member of Speech Pathology Australia.

## 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.*

### 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

### Good Practice Points:

- 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 with the assessment team to ensure that assessments are not repeated, and the client is not asked to repeat information unnecessarily.
- 57.4 The practitioners from the assessment team should also be given any background information required to understand the client and their context including any enablers and/or barriers to the client's activities and participation.
- 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 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 across 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.

## 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

### 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 observations and 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

### Good Practice Points:

- 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 gender-related 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 clients 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, and 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.

### 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

#### Good Practice Points

63.1 Given that 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, take into account information from both evaluations.
- Integrate and weigh the available evidence against each diagnostic criterion (according to the current version of the DSM or ICD) including specifiers (e.g., with or without accompanying intellectual impairment), if appropriate.
- Test alternative explanations for characteristics that may warrant co-occurring or differential diagnosis or alternative clinical pathways.
- Consider ways that intersectionality of personal and contextual factors may influence a client's presentation, strengths, and supports needs, such as being a member of the LGBTQI+ community, being culturally and linguistically diverse, and the presence of other psychosocial factors.

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 is 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 can also 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

#### Good Practice Points:

- 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 specifiers when using DSM-5-TR criteria, if appropriate.
  - 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 when using DSM-5-TR criteria, if appropriate.
  - 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, noting of specifiers (including current support needs) if appropriate.
  - 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/attention deficit hyperactivity disorder 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



# Future directions

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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.

## 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 the 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:

**Competency framework:** Research is needed to explore the development of a competency-based framework for assessment and diagnosis of autism in Australia. This could include examining what competencies are required, how they could be assessed, and how use of the framework could be regulated; as well as studies examining the relative strengths of models employing such a framework compared to existing Recommendations with respect to supporting timely, accurate, accessible, and equitable diagnosis.

**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, have intellectual disability, and/or have 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).

**Culturally-affirming 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 in order to be accurate and culturally-affirming.

**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.

**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.

**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.

## 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, 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.



## 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 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). Practitioners should also consider availing themselves of the increasing opportunities for training developed and delivered by, and in partnership with, autistic people and people with lived experience of autism including parents and caregivers.

**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 Comprehensive Needs 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



# Glossary

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## **Acceptability**

The extent to which the client perceives a particular service to be appropriate and meets 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. Autism CRC funded the development of this Guideline. Autism CRC's website is: [autismcrc.com.au](http://autismcrc.com.au)

**Client**

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.

**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 from 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 Organization, 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 describe the best practice approach for developing practice guidelines in Australia (called 'Guidelines for Guidelines').

## **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**

Any action that has the effect of restricting the rights or freedom of movement of a person with disability. In Australia, restrictive practices are subject to regulation. Restrictive practices include:

- 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 practitioner 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.

## **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 provider 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

Example no.	Description of the Assessment Process	Clinicians in the Assessment Process			
		Assessment of Functioning	Medical Evaluation	Lead Practitioner Diagnostic Evaluation	Consensus Team Diagnostic Evaluation
1	An occupational therapist is providing therapy to a 4-year-old male with gross motor difficulties for whom autism is queried. The occupational therapist conducts an assessment of functioning in partnership with a speech pathologist within the same clinic. In this public-sector setting, the occupational therapist is able to refer the client to a service paediatrician, who conducts the medical evaluation and lead practitioner diagnostic evaluation. Based on the client's presentation, and input from the occupational therapist and speech pathologist, the paediatrician is able to reach diagnostic outcome with certainty.	<b>Clinician 1:</b> Occupational Therapist  <b>Clinician 2:</b> Speech Pathologist	<b>Clinician 3:</b> Paediatrician	<b>Clinician 3:</b> Paediatrician	
2	A child health nurse identifies early developmental concerns for an 18-month-old female. The child health nurse conducts the assessment of functioning and suggests the client consult a GP to obtain a referral to a private paediatrician, who performs a medical evaluation and a lead practitioner diagnostic evaluation, but is unable to reach a diagnostic outcome with high confidence. The paediatrician forms a consensus diagnosis team by inviting additional clinicians with expertise in the area of diagnostic uncertainty (in this case, a developmental/educational psychologist and speech pathologist). This team is unable to reach consensus on a diagnostic outcome and recommends reassessment upon a significant change in function or presentation, or when new information becomes available.	<b>Clinician 1:</b> Nurse	<b>Clinician 2:</b> Paediatrician	<b>Clinician 2:</b> Paediatrician	<b>Clinician 3:</b> Occupational Therapist  <b>Clinician 4:</b> Psychologist

Example no.	Description of the Assessment Process	Clinicians in the Assessment Process			
		Assessment of Functioning	Medical Evaluation	Lead Practitioner Diagnostic Evaluation	Consensus Team Diagnostic Evaluation
3	A 14-year-old male is referred by a GP to a paediatrician for concerns regarding social isolation and tic behaviours. The paediatrician conducts both the assessment of functioning and medical evaluation, and explores autism symptoms through a lead practitioner diagnostic evaluation. The paediatrician is unable to reach a diagnostic outcome with high confidence and invites additional clinicians to form a consensus diagnosis team (in this case a clinical psychologist and occupational therapist) who, together, are able to reach a consensus decision on the diagnostic outcome.	Clinician 1: Paediatrician	Clinician 1: Paediatrician	Clinician 1: Paediatrician	<div>Clinician 2: Occupational Therapist</div> <div>Clinician 3: Psychologist</div>
4	During the assessment of a 21-year-old male admitted to a forensic mental health service, a psychiatrist notes some of the presenting signs and characteristics may be explained by autism. The psychiatrist undertakes the Assessment of Functioning and Medical Evaluation, but determines that she does not have sufficient autism-specific expertise to conduct a diagnostic evaluation. The psychiatrist refers the client to a second psychiatrist with expertise in this area to complete the Lead Practitioner Diagnostic Evaluation. This psychiatrist is able to confirm with high confidence that the male does not meet all the required autism criteria, but does meet the criteria for a separate psychiatric disorder.	Clinician 1: Psychiatrist	Clinician 1: Psychiatrist	Clinician 2: Psychiatrist	
5	A 35-year-old female has queried an autism diagnosis for herself after her child is diagnosed as being autistic, and asks her child's speech pathologist how she can initiate an assessment process. The speech pathologist explains the process and refers her to her general practitioner to complete the Medical Evaluation and a clinical psychologist to conduct an Assessment of Functioning. The same clinical psychologist performs a Lead Practitioner Diagnostic Evaluation and is able to reach a diagnostic outcome with high confidence.	Clinician 1: Clinical Psychologist	Clinician 2: General Practitioner	Clinician 1: Clinical Psychologist	

Example no.	Description of the Assessment Process	Clinicians in the Assessment Process			
		Assessment of Functioning	Medical Evaluation	Lead Practitioner Diagnostic Evaluation	Consensus Team Diagnostic Evaluation
6	Parents present to their general practitioner with concerns regarding their 3-year-old daughter's development and behaviour. She refuses to speak to unfamiliar people, has a very restricted diet, appears to have delayed fine and gross motor skills, and has challenges with routines such as brushing her teeth and getting to sleep at night. Based on the child's presentation and the family's resources, the general practitioner provides a referral to a public-sector Child Development Service and shares outcomes of a Medical Evaluation with the service. Members of a multidisciplinary team (occupational therapist, speech pathologist, paediatrician) conduct an Assessment of Functioning and Consensus Team Diagnostic Evaluation, and are able to reach a diagnostic outcome with high confidence.	<b>Clinician 2:</b> Occupational Therapist  <b>Clinician 3:</b> Speech Pathologist  <b>Clinician 4:</b> Paediatrician	<b>Clinician 1:</b> General Practitioner		<b>Clinician 2:</b> Occupational Therapist  <b>Clinician 3:</b> Speech Pathologist  <b>Clinician 4:</b> Paediatrician
7	A 30-year-old female is referred by a general practitioner to a psychiatrist after identifying potential autism characteristics in herself after her daughter recently received diagnoses of autism and co-occurring ADHD. The general practitioner shares outcomes from a Medical Evaluation with the psychiatrist, who conducts an Assessment of Functioning and explores autism characteristics and differential diagnosis through a Lead Practitioner Diagnostic Evaluation. Based on the client's Medical Evaluation, presentation, and developmental history, the psychiatrist is able to reach a diagnostic outcome with high confidence.	<b>Clinician 2:</b> Psychiatrist	<b>Clinician 1:</b> General Practitioner	<b>Clinician 2:</b> Psychiatrist	



Example no.	Description of the Assessment Process	Clinicians in the Assessment Process			
		Assessment of Functioning	Medical Evaluation	Lead Practitioner Diagnostic Evaluation	Consensus Team Diagnostic Evaluation
8	A clinical psychologist who practices in a multidisciplinary clinic is providing support to a 13-year-old female in relation to educational and social challenges. The client’s combination of strengths and challenges leads him to request input from a nurse practitioner, speech pathologist, and occupational therapist who together conduct an Assessment of Functioning. The nurse practitioner also completes a Medical Evaluation. Based on all information gathered and following consultation, the clinical psychologist proceeds with a Lead Practitioner Diagnostic Evaluating, resulting in a diagnostic outcome with high confidence.	<div>Clinician 1: Clinical Psychologist</div> <div>Clinician 2: Nurse practitioner</div> <div>Clinician 3: Speech Pathologist</div> <div>Clinician 4: Occupational Therapist</div>	<div>Clinician 2: Nurse practitioner</div>	<div>Clinician 1: Clinical Psychologist</div>	

## Appendix 2.2:

# Expertise, training, and membership for clinicians commonly involved in the assessment team

Practitioner	Skills and expertise	Training	Registration or membership
<b>Paediatrician</b>	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).
<b>Psychiatrist</b>	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).

Practitioner	Skills and expertise	Training	Registration or membership
<b>Neurologist</b>	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).
<b>Psychologist</b>	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).
<b>Speech pathologist</b>	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.

Practitioner	Skills and expertise	Training	Registration or membership
<b>Occupational therapist</b>	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).
<b>Social worker</b>	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, and may hold additional credentials (e.g., mental health, disability).
<b>Nurse practitioner</b>	Registered nurses with the experience, expertise and authority 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 a minimum 5,000 hours experience at the clinical advanced nursing practice level.	General registration as a registered nurse 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

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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
- registered nurse
- nurse practitioner (including mental health nurse practitioner)
- occupational therapist
- ophthalmologist
- optometrist
- paediatrician
- physiotherapist
- preschool or early childhood teacher
- primary or secondary school teacher
- psychiatrist
- psychologist
- rehabilitation counsellor
- sleep and respiratory physician
- social worker (including those who hold additional credentials, such as in mental health and disability)
- 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
<b>Social interaction and/or communication domain(s)</b>	Receptive language (e.g., comprehension of the verbal and non-verbal communication of others)
	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)
<b>Repetitive patterns of behaviour, interests, or activities domain</b>	Sensory motor assessment (e.g., presence of hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment)
	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)

Assessment focus	Types of assessment
<b>Possible differential or co-occurring diagnosis</b>	Cognitive and/or neurodevelopmental assessment (e.g., intelligence, learning capability, visual perception, memory, executive functioning)
	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 and/or psychological 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



### **Innovation**

Solutions for long term challenges



### **Evidence**

Truth in practice



### **Independence**

Integrity through autonomy



### **Cooperation**

Capturing opportunities together



# AutismCRC

Independent national source of evidence for best practice



[autismcrc.com.au](https://autismcrc.com.au)