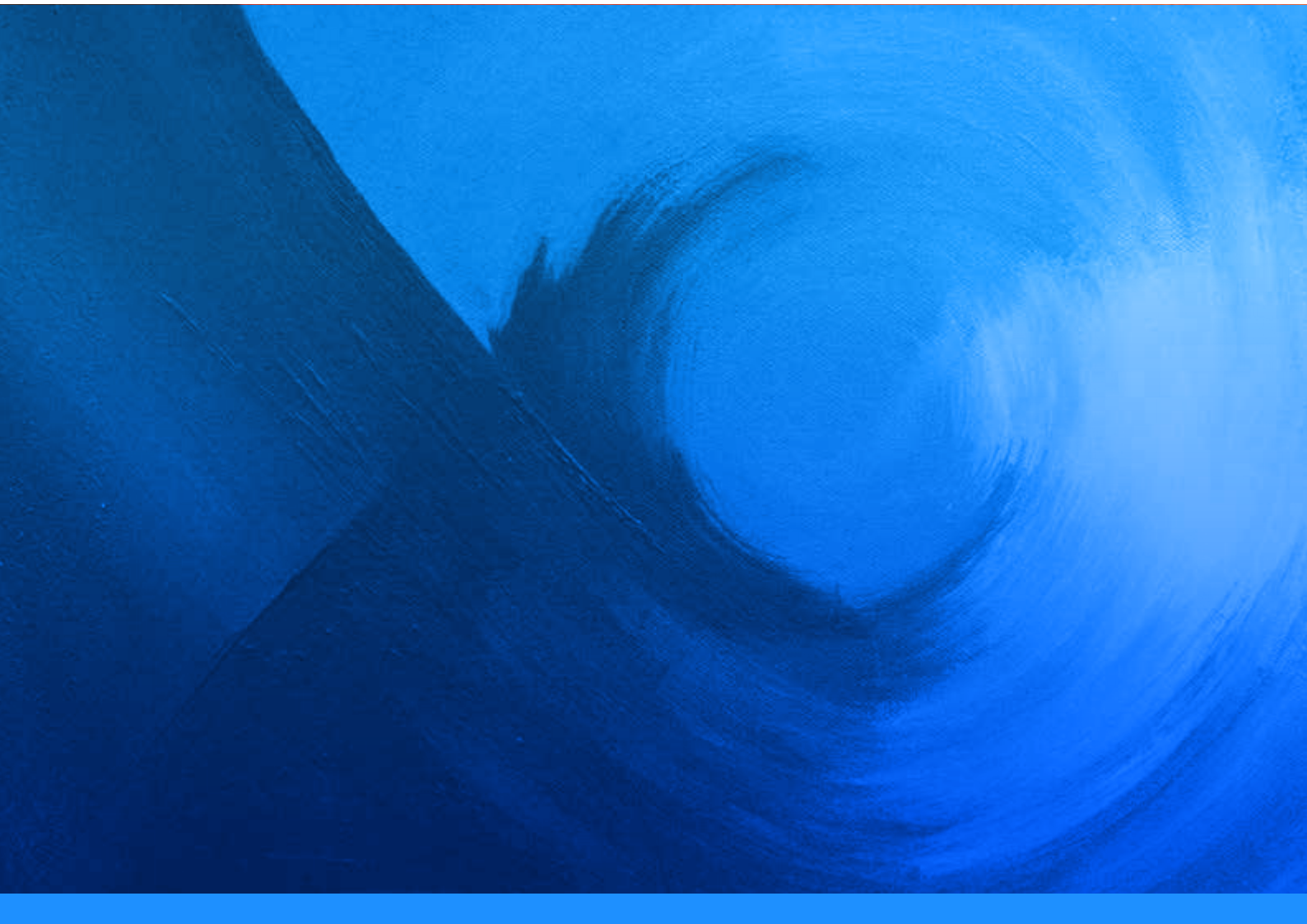




Information for parents and caregivers

National Guideline

For the assessment and diagnosis of autism in Australia



Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum. We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community. Autism CRC was established in 2013 as the world's first national, cooperative research effort focused on autism under the Australian Government's Cooperative Research Centres (CRC) Program. We receive funding from a number of sources, including the Australian Government. Autism CRC is no longer part of, or associated with, the CRC Program.

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Welcome

The **National Guideline for the assessment and diagnosis of autism in Australia (the Guideline)** sets out **66** Recommendations for how assessments, that consider a diagnosis of autism, should occur.

This booklet is designed to help parents and caregivers know what to expect and experience during a clinical assessment and diagnosis of autism, based on the best practice Recommendations in the Guideline. It also provides tips for engaging with practitioners, examples of what good practice should look like, and links to additional information.

Each person's assessment journey will be different. However, everyone should experience an assessment that is **safe, helpful, respectful, appropriate, informative, individualised, and comprehensive. It should be led by competent practitioners who use evidence-based practices and modern approaches whilst respecting each person's preferences and way of interacting with the world.**

About the Guideline

The Guideline helps ensure that practitioners involved in assessment use best practice.

It was developed with extensive community consultation and reviewing the existing evidence. Notably, members of the autistic and autism communities generously shared their experiences, insights, and views to inform the Guideline.

Publication approval by the National Health and Medical Research Council (NHMRC) means the Guideline meets the highest national standard.

Tips



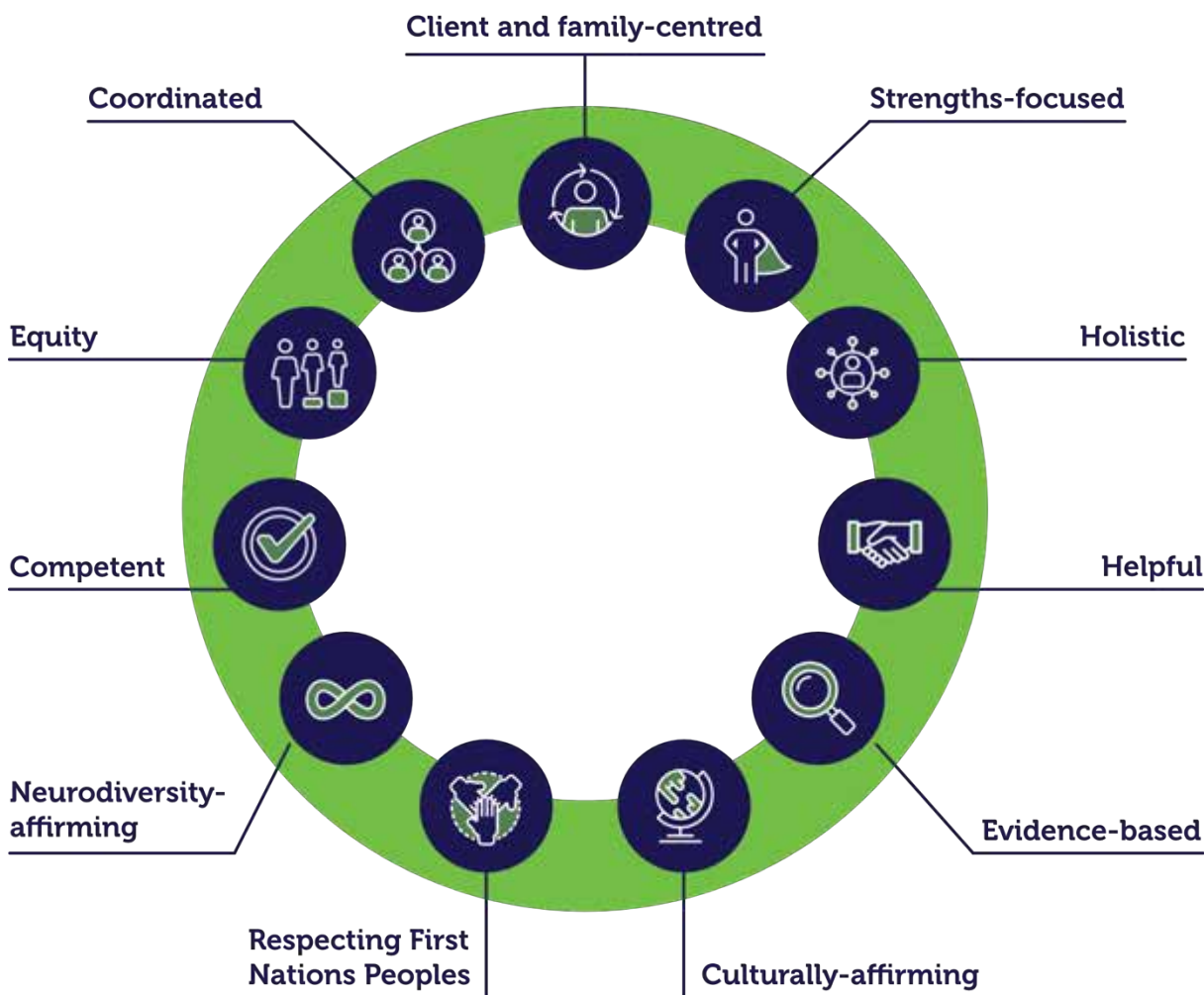
- Referring directly to the [Guideline](#) is highly encouraged to understand what a proper assessment involves, including who is involved, and how, where, and when different parts of the assessment are conducted. Having this knowledge should make you feel more empowered and informed regarding the assessment and diagnosis of autism.
- Whilst acknowledging the importance of clinical terminology, the Guideline refers to 'autism' due to an important shift 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 recommends that **practitioners use strengths-based language** and frame diagnostic criteria in a **neurodiversity-affirming** way when talking about autism. For example, 'difficulties' or 'challenges' instead of 'deficits' or 'impairment'.

Guiding Principles

Guiding Principles (Recommendations 1-11) include all parts of the assessment and diagnostic process. Your practitioner should follow these principles when supporting your child or the person in your care.



Guiding Principles provide a framework through which practitioners can make decisions in relation to all aspects of the assessment and diagnostic process for autism. You can find out more about the practical ways your child's practitioner or assessment team might apply the 11 Guiding Principles in the personal reflection section of this booklet on page 17.

Foundations of assessment

The **Foundations of Assessment (Recommendations 12-36)** outlined below should underpin all elements of the assessment and diagnostic process experienced by you and your child or the person in your care.



Process

A clear and consistent process



Knowledge, skills, training, supervision and regulation

Delivered by people with appropriate knowledge, skills, attitudes, training, supervision, and regulation



Collecting information

Thorough information collection



Settings (clinic, community and telehealth)

In settings that are appropriate and accessible



Sharing information

With information that is helpful respectful and accessible



Referral for supports

With referral to supports when needed



Quality and safety

High quality with appropriate safeguards



Tip

An assessment setting could take place in a home, clinical, educational, social, telehealth, recreational or cultural environment, as long as it supports the privacy, safety, and comfort of an individual and their family.

Journey overview



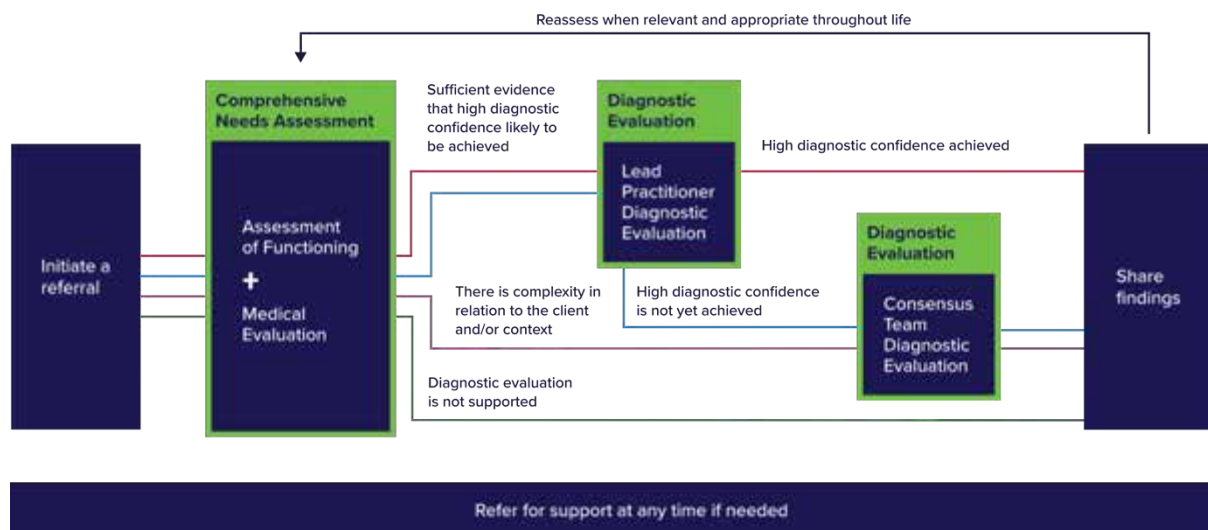
The starting point for every journey is knowing that each child and family is unique, and the journey through an assessment and possible diagnosis will differ for everyone. However, the Guideline defines a clear process that empowers you to be fully informed and confident that what you should experience is best practice.

For some children, the assessment leads to a clear finding of whether or not autism is an appropriate diagnosis. However, the finding may be unclear for others, and further assessment may be needed. For example, the team may be expanded to include practitioners with additional expertise or occur over a longer period with more appointments.

It is common for an assessment that considers autism to not result in a diagnosis of autism. For example, a child being very reluctant to engage in social situations may be better explained solely by anxiety.

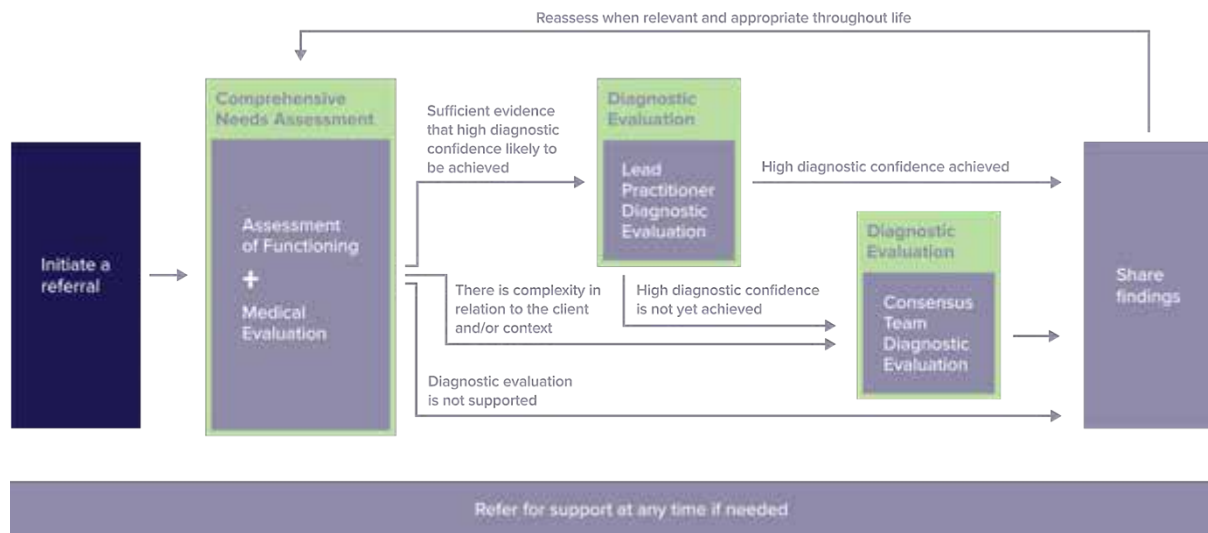
At every stage, the practitioners you work with should talk to you and your child (when appropriate) about what they are doing, what they are finding, and what they recommend should happen next. They should explain the reasons for their decisions and encourage you to ask questions.

The four coloured paths below represent possible different journeys as recommended in the Guideline. Depending on the individual person and their support needs and presentations, the process is flexible to promote timely and accurate assessment and diagnosis.



The process for assessment and diagnosis of autism should include a **Referral (Recommendations 37-41)**, a **Comprehensive Needs Assessment (Recommendations 42-53)** that includes an **Assessment of Functioning and Medical Evaluation**, and a **Diagnostic Evaluation (Recommendations 54-66)** when appropriate. A **referral for supports** made at any stage a need is identified.

Starting your journey: Initiating a referral



Why seek a referral?

As a parent or caregiver, you can speak to your child's health practitioner (for example, General Practitioner or Aboriginal Health worker) about any questions or concerns about your child's development. For some parents or caregivers, you may be working with a health practitioner for other reasons (for example, seeking support with learning to communicate) and that practitioner may suggest further assessment.

Either way, the health practitioner should listen to and discuss your questions and concerns and take a broad look at your child's or the person in your care's development, health, and wellbeing. To start with, they may do this themselves or refer you to another health practitioner.

If the practitioner thinks your child is showing characteristics of autism, they should then begin to follow the assessment and diagnostic process outlined in the Guideline. It is important to remember, however, that they will not just be thinking about autism. Instead, they will be thinking about all the possible explanations for how your child is developing all the way through the assessment process.

Good Practice Point



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.**

Preparing for your appointment

Tips



- Before your appointment, it's a good idea to create a list of topics you want to discuss and questions you might have. You might like to start by thinking about what you and your child need from an assessment and why you are seeking one. You can use the Good Practice Points mentioned above as a starting point and write the list down in the note section at the end of this document. This will help you stay organised and make the most of your appointment.
- Most parents and caregivers want to talk about their child using language that values and affirms them. If you feel uncomfortable with the way that your practitioner is talking about or with your child, you can talk with them about your preferences and needs. Awareness and use of neurodiversity-affirming and strengths-based language is growing among practitioners and across disciplines. If you experience something different, it is okay to communicate your preferences with the practitioner.
- It is important to note that if, at any point, you feel like your questions have not been answered or your concerns are not addressed, it is okay to seek a second opinion.

What information may be collected?

Your practitioner should collect information about your child that helps them understand whether a referral for assessment that considers autism may be appropriate and desirable.

Good Practice Point

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.**

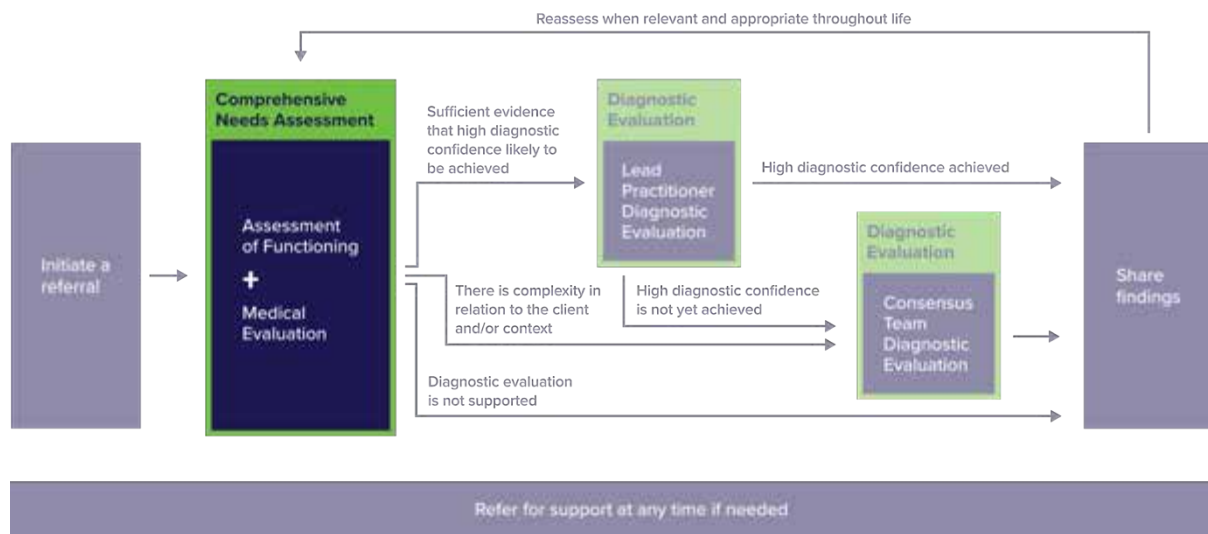


Tip

You are encouraged to take notes in the space provided at the end of this booklet. Your notes may help guide your discussion with the practitioner when you meet with them next. This can help you to get the best out of your time with the practitioner and ensure you don't forget any questions or concerns you have regarding your child or the person in your care.

Next steps: What's involved in a Comprehensive Needs Assessment?

The next step within the process is a **Comprehensive Needs Assessment** which comprises an **Assessment of Functioning** and a **Medical Evaluation**.



The **Comprehensive Needs Assessment** is a core component of all assessments for autism and seeks to understand all relevant aspects of the child's **characteristics, functioning, context, strengths, and support needs**.

What is an Assessment of Functioning?

An **Assessment of Functioning** involves developing a detailed understanding of the abilities of your child or the person in your care, their strengths, and any support needs they might have across a broad range of areas.

These may include:

- cognitive abilities
- speech and language function
- daily living skills
- social relationships
- educational environment.

The assessment process may include standardised questionnaires, clinical interviewing (in depth conversations with a practitioner based on set questions), and observations.

What is a Medical Evaluation?

A **Medical Evaluation** involves a physical examination and other medical tests to understand if there could be medical causes for the behaviours or characteristics that prompted the referral. The Medical Evaluation should aim to answer your questions and may help identify the need for specialist referrals, assessments, and support as part of ongoing care.

What information may be collected?

During a Comprehensive Needs Assessment the following information may be collected about your child or the person in your care:

- Medical and health history
- Family history and family function
- Developmental and educational history
- Autism-specific characteristics
- 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.



Who are the eligible professionals recommended to be involved in a Comprehensive Needs Assessment?

Profession	Comprehensive Needs Assessment	
	Assessment of Functioning	Medical Evaluation
Medical practitioner	✓	✓
Psychologist	✓	✗
Registered nurse	Specified ^a	Specified ^a (collaborate)
Occupational therapist	✓	✗
Social worker	✓	✗
Speech pathologist	✓	✗

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

^a 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.



At every stage, the practitioners you work with should talk to you and your child (when appropriate) about what they are doing, what they are finding, and what they recommend should happen next. They should explain the reasons for their decisions and encourage you to ask questions. Their job is to listen and to help you and your family to be fully informed.

You should always feel empowered to ask for what you and your child and family need.

Guideline reference

You may like to refer to the [Guideline](#) for more in-depth detail regarding the information collected (Good Practice Points 45.1 - 45.9)



You may like to refer to Appendix 2.2 of the Guideline to review the expertise, training and memberships for practitioners commonly involved in an assessment team.

Note: Other practitioners might contribute information relevant to the assessment process. Please refer to Appendix 2.3 of the Guideline to see a non-exhaustive list.

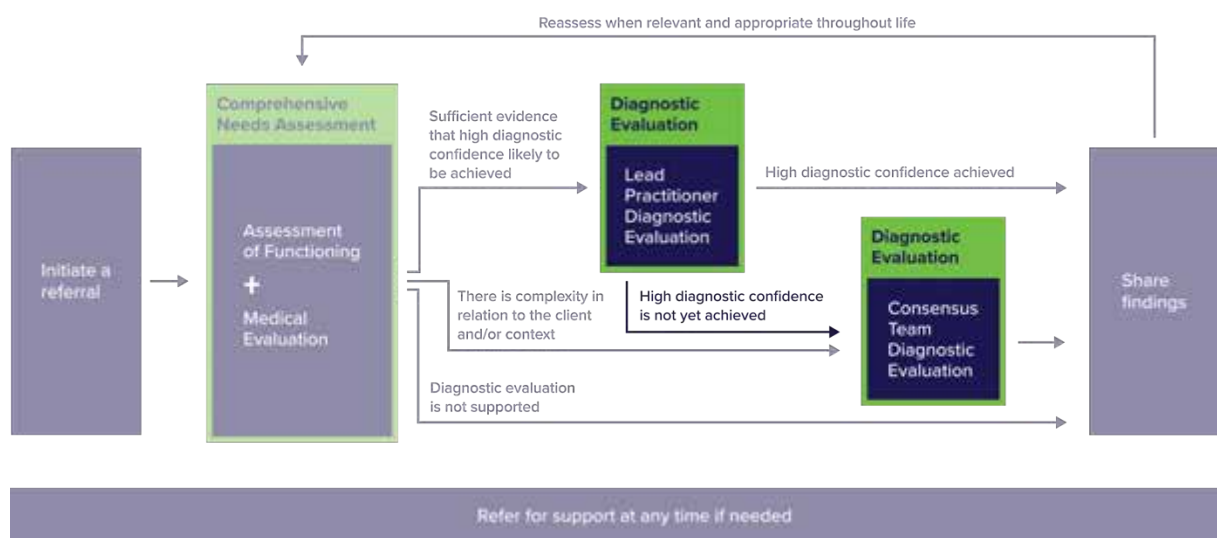
It is important to keep in mind that a thorough assessment should not solely focus on autism. Instead, it should take into account all potential reasons for any behaviours or experiences. **If the findings of the Comprehensive Needs Assessment suggest a possible diagnosis of autism, the Diagnostic Evaluation should be started.**

Undertaking a Diagnostic Evaluation

If a diagnostic evaluation is suggested for your child or a person in your care, your practitioner may recommend:

- A Lead Practitioner Diagnostic Evaluation, or
- A Consensus Team Diagnostic Evaluation

This will depend on which is likely to result in a more timely and accurate evaluation.



You might be referred for a **Lead Practitioner Diagnostic Evaluation** when there is high confidence that a diagnosis of autism and/or other conditions is (or is not) appropriate. **Although a practitioner leads the process, it is recommended that at least one other relevant practitioner should be consulted.**

Alternatively, you might be referred for a **Consensus Team Diagnostic Evaluation** if you have a complex history or clinical presentation (for example, subtle characteristics and/or indications that multiple diagnoses may be relevant). This might also be preferable when a Lead Practitioner Diagnostic Evaluation is unavailable or if it seems unlikely that a diagnostic decision will be reached with high confidence through a Lead Practitioner approach.



What are practitioners referring to when it comes to diagnostic criteria?

In Australia, practitioners currently rely on two sets of commonly used diagnostic criteria included within:

- the **Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5- TR)** or
- the **International Classification of Diseases 11th Edition (ICD-11)**

When your child is assessed for autism, they may receive a diagnosis of Autism Spectrum Disorder based on the criteria listed in the DSM-5-TR or ICD-11. The language used in these criteria can sound overwhelming and confronting but we've summarised the information here for you.

Autism Spectrum Disorder is the collective diagnostic term for a group of neurodevelopmental conditions. Whilst every autistic person is unique, there are certain characteristics which are common to all autistic people. Autism is 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 characteristics of autism are often present before 3 years of age but may not be recognised until the school years or later in life as social and cognitive demands increase.

Who are the eligible professionals recommended to be involved in a Diagnostic Evaluation?

Profession	Diagnostic Evaluation	
	Lead Practitioner	Consensus Team
Medical practitioner	Specified ^b	✓ ^d
Psychologist	Specified ^c	✓ ^d
Registered nurse	✗	✗
Occupational therapist	✗	✓ ^d
Social worker	✗	✗
Speech pathologist	✗	✓ ^d

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

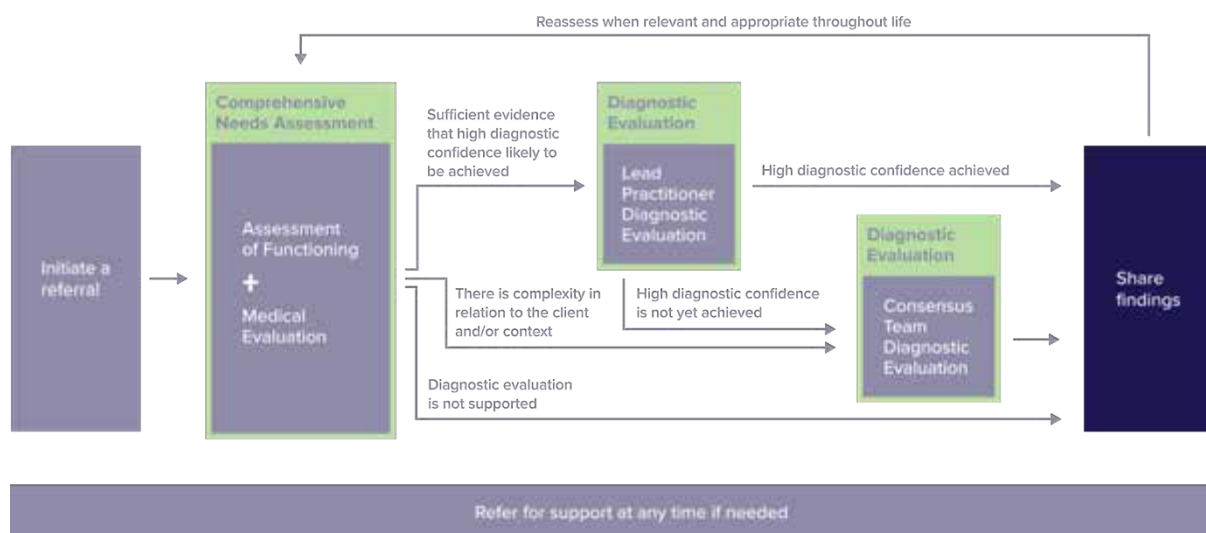
^b To conduct a Diagnostic Evaluation, medical practitioners are recommended to have a specialist registration in the field of community child health, general paediatrics, psychiatry or neurology, or have general registration with at least six years of relevant experience in the assessment and diagnosis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

^c 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.

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

Sharing findings and accessing supports

Findings should be shared throughout the process, at the final step in the process, or whenever it is determined that diagnostic evaluation is not supported. **Findings should be shared with you regarding your child or person in your care in a way that is accurate, understandable, and is affirming of your child and your family.**



After an assessment

After the assessment, the Guideline recommends that the practitioners provide you with a **written report**.

The report will summarise the information collected during the assessments and what this information means. It will also explain any decisions that have been made about a diagnosis and suggest the next steps for accessing support services.

Whatever the outcome of the assessment, your child is the same person today, as they were yesterday. Nothing has changed; you just have more information to support them and yourself to thrive.

Remember that there is no rush to do anything immediately. It is okay to sit with the information shared in the written report and take the time to process it in your own way.

Accessing support

- Accessing support can, and should, happen at any time it is needed.
- Practitioners you work with should ask about what, if any, supports you already have in place for your child or person in your care, and if you need additional supports
- Your practitioner should refer your family for the support needed, as soon as you or they identify a need.

National Guideline for supporting autistic children and their families

Autism CRC has also developed a **National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia (Supporting Autistic Children Guideline; SACG)**. The Guideline defines evidence-based practices that promote a child's development, their participation in childhood activities, and their wellbeing. It is primarily focused on the delivery of non-pharmacological supports (that means supports other than medicines) to children aged 0-12 years in community and clinical settings, and doing so in ways that are safe, effective, and desirable to children and their families.

We highly recommend that you take the time to review this Guideline and its supporting resources if accessing support for your child or the person in your care, including the SACG **Journey Planner for parents and caregivers**.



Tip

You can ask for a referral for support at any stage throughout the process.

Assessments should be repeated when relevant and appropriate throughout an individual's lifetime.



More information

If you would like to extend your learning on the best practice Guidelines there are short online courses available through Autism CRC:

- autismcrc.com.au/best-practice/assessment-and-diagnosis/eLearning-resources
- autismcrc.com.au/best-practice/supporting-children/for-community

Autism CRC: autismcrc.com.au

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.

Reframing Autism: reframingautism.org.au

Reframing Autism: Autistic-developed information, courses, and resources about autism, including personal accounts.

Autism Connect: amaze.org.au/autismconnect

Online chat and phone service to support families and individuals to understand autism, and pathways for support.



Tip

Always refer to the Guideline for more information and to further expand on the information in this booklet.

To register for access to the assessment and diagnosis Guideline, visit:
autismcrc.com.au/best-practice/assessment-and-diagnosis



Personal reflection

When going through the assessment and diagnostic process with your child, you should expect that the Guiding Principles that underpin the Guideline will form part of your child's journey and interactions with practitioners. However, we know it might be tricky to think about the practical ways your child's practitioner or assessment team might apply the Guiding Principles.

The questionnaire is designed to help you reflect on the principles and to think about what a beneficial assessment and diagnostic process might look, sound, and feel like for you and your child. Every person – and every family – is different, so this document might help you to personalise your child's experience and journey.


You may wish to complete this document before your initial meeting with the practitioner/s as a personal reflection and/or share your thoughts with the practitioner/s. It may help them to understand you and your child's needs and expectations.

This document was co-produced with members of the autistic community, and we thank them for their valuable input, guidance, lived expertise and support in creating the following questionnaire and example responses.

The text included below are examples and prompts for you to consider, and you can also fill in your own thoughts using the blank template provided.



Guiding Principles questionnaire example

 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.	
Considerations	Examples/Responses
This might look like...	<p>The practitioner asks me my reasons for exploring an autism assessment for my child. The practitioner confirms their understanding of my reasons for exploring an assessment for my child, and validates these, by including direct reference to these reasons in any information shared or reports I receive throughout the assessment and diagnostic process.</p> <p>The practitioner checks in with me about my child's sensory and communication needs, before our meeting or an appointment.</p>
Prompts and examples to consider...	<ul style="list-style-type: none"> • What things do I want to learn about my child from this assessment and diagnostic process? • What specific areas would I like additional support in for my child? • How can the assessment and diagnostic process help me to understand my child's unique profile and needs? • What do I need to make this process beneficial for my child and family? For example, a written summary of verbal conversations, an agenda in advance of what will be discussed, a low-sensory environment, an introduction prior to the appointment to those who will be present in the appointment; support with knowing where to park, how to pay, how long an appointment will take.
How important is this principle to you in experiencing a successful diagnostic process?	<p><input type="checkbox"/> Extremely important</p> <p><input type="checkbox"/> Very important</p> <p><input type="checkbox"/> Moderately important</p> <p><input type="checkbox"/> Slightly important</p> <p><input type="checkbox"/> Not at all important</p> <p><input type="checkbox"/> Not applicable</p>
For this principle to be achieved for my family, it will look / sound / feel like...	<p>For example, I will feel like the practitioner actively listens to my child's experiences and takes what is shared seriously.</p> <p>I will not experience a dismissive approach regarding my concerns about my child. Instead, the practitioner will talk about my child's experiences in ways that are respectful and validating.</p>



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.

Considerations	Examples/Responses
<p>This might look like...</p>	<p>The practitioner helps me to explore my child's strengths by actively asking me about what brings my child joy, when my child feels satisfied and content, what my child's passions are, and what things my child excels in.</p> <p>The practitioner uses neuro-affirming and strengths-based language that does not stigmatise autism so that my child does not feel 'broken' or 'wrong'.</p> <p>The practitioner invites me to a parent-only appointment so that I do not need to discuss my child's challenges in front of them.</p>
<p>Prompts and examples to consider...</p>	<ul style="list-style-type: none"> • Can I identify my child's strengths and passions? Do I need the practitioner to support me to do this so we can both be strengths-based? • How would I like my child's challenges to be discussed so that I can still remember they have strengths? • Where else can my child go when the practitioner or I need to discuss vulnerable and/or challenging subjects? • How would I like to receive the diagnostic report, especially if it is not entirely strengths-based? For example, I would like a face-to-face appointment to discuss the report before I read it, so the practitioner can reframe any deficit-based language.
<p>How important is this principle to you in experiencing a successful diagnostic process?</p>	<p><input type="checkbox"/> Extremely important</p> <p><input type="checkbox"/> Very important</p> <p><input type="checkbox"/> Moderately important</p> <p><input type="checkbox"/> Slightly important</p> <p><input type="checkbox"/> Not at all important</p> <p><input type="checkbox"/> Not applicable</p>
<p>For this principle to be achieved for my family, it will look / sound / feel like...</p>	<p>For example, I will hear that I am invited to share what my child is good at, and what brings my child joy and meaning.</p> <p>I will feel that I have opportunities to share my child's most vulnerable and challenging moments without them present.</p>



Holistic: Assessments 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.

Considerations	Examples/Responses
<p>This might look like...</p>	<p>The practitioner asks me about my child’s co-occurring conditions (whether diagnosed or suspected) and the impact these have on my child’s daily life.</p> <p>The practitioner will listen without judgment when I share my memories and past experiences about my child, and accept them as true.</p> <p>The practitioner will ask me about how my child experiences different contexts and will help to explore the factors impacting on these experiences.</p>
<p>Prompts and examples to consider...</p>	<ul style="list-style-type: none"> • Do I feel comfortable involving other family members in my child’s assessment and diagnostic process to complement or confirm my memories and experiences? • What do I imagine my child’s future looks like if they’re living their best life? How might this assessment and diagnostic process help my child to achieve that future?
<p>How important is this principle to you in experiencing a successful diagnostic process?</p>	<p><input type="checkbox"/> Extremely important</p> <p><input type="checkbox"/> Very important</p> <p><input type="checkbox"/> Moderately important</p> <p><input type="checkbox"/> Slightly important</p> <p><input type="checkbox"/> Not at all important</p> <p><input type="checkbox"/> Not applicable</p>
<p>For this principle to be achieved for my family, it will look / sound / feel like...</p>	<p>For example, I will feel that our past diagnostic experiences are considered during this assessment and diagnostic process, including potential re-evaluation of past diagnoses to a diagnosis of autism and/or other conditions.</p> <p>I will hear the practitioner asking respectful questions about my child’s past, checking in on their wellbeing, and being sensitive to potential triggers and trauma.</p>



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.

Considerations	Examples/Responses
<p>This might look like...</p>	<p>The practitioner asks me explicitly why I am seeking an assessment for my child and helps me to understand what they can offer through the process to fulfil those reasons.</p> <p>The practitioner talks with me about what pathways to support are available, whether my child receives a diagnosis of autism or not, and provides guidance and high-quality information that helps me to access services to support my child's needs.</p>
<p>Prompts and examples to consider...</p>	<ul style="list-style-type: none"> • Do I know what I want to 'get out' of the assessment and diagnostic process? For example, financial assistance, community and connection, self-knowledge, increased wellbeing. How can the practitioner help me to think about my 'whys' for seeking an autism diagnosis for my child? • Do I know what support is available if my child receives a diagnosis of autism and/or other conditions? If not, what sorts of supports do I generally find useful? For example, courses, support, or community groups, reading material, podcasts. • What questions do I have about autism? How do I think I would like those questions to be answered?
<p>How important is this principle to you in experiencing a successful diagnostic process?</p>	<p><input type="checkbox"/> Extremely important</p> <p><input type="checkbox"/> Very important</p> <p><input type="checkbox"/> Moderately important</p> <p><input type="checkbox"/> Slightly important</p> <p><input type="checkbox"/> Not at all important</p> <p><input type="checkbox"/> Not applicable</p>
<p>For this principle to be achieved for my family, it will look / sound / feel like...</p>	<p>For example, I will have an opportunity to ask questions, as well as to have questions asked of me. I will have time to reflect on questions I might have and can ask them at another time or have a way to ask questions via email or text in case they don't occur to me 'in the moment' at an appointment.</p>



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.

Considerations	Examples/Responses
This might look like...	<p>The practitioner helps me to understand why a particular assessment or diagnostic practice has been chosen, and why it is suitable for my child.</p> <p>The practitioner references the lived experiences of autistic people in helping me to understand my child's strengths, needs, supports, aspirations, and challenges.</p>
Prompts and examples to consider...	<ul style="list-style-type: none">• What types of evidence are most important to me?• How important is it to me to include lived experiences and expertise in how I understand my child?• Does the explanation they give make sense to me? Is the evidence they are using relevant to my child or person in my care?
How important is this principle to you in experiencing a successful diagnostic process?	<p><input type="checkbox"/> Extremely important</p> <p><input type="checkbox"/> Very important</p> <p><input type="checkbox"/> Moderately important</p> <p><input type="checkbox"/> Slightly important</p> <p><input type="checkbox"/> Not at all important</p> <p><input type="checkbox"/> Not applicable</p>
For this principle to be achieved for my family, it will look / sound / feel like...	<p>For example, if I am an autistic parent, I will have an opportunity to disclose my own autistic identity, and to bring my personal knowledge and experience to appointments about my child.</p>



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.

Considerations	Examples/Responses
<p>This might look like...</p>	<ul style="list-style-type: none"> • A practitioner who is able to acknowledge my culture and learn about it. • A practitioner who is able to be curious about cultural differences and incorporate these into their approach • A place where a parent or caregiver is able to be open and respected for their cultural differences.
<p>Prompts and examples to consider...</p>	<ul style="list-style-type: none"> • How does my culture and community think about neurodevelopmental differences? • How has my culture impacted my view of autism? • How can my community and culture support my child with autism? • What challenges may my cultural differences place on my child's journey with autism?
<p>How important is this principle to you in experiencing a successful diagnostic process?</p>	<p><input type="checkbox"/> Extremely important</p> <p><input type="checkbox"/> Very important</p> <p><input type="checkbox"/> Moderately important</p> <p><input type="checkbox"/> Slightly important</p> <p><input type="checkbox"/> Not at all important</p> <p><input type="checkbox"/> Not applicable</p>
<p>For this principle to be achieved for my family, it will look / sound / feel like...</p>	<p>As a parent or caregiver, I would be provided with time to consider a diagnosis of autism in my children. In the meantime, we would be provided with supports for my child to flourish and that respects their differences. I would be provided with information that I can share with my family members that explains what autism is in a culturally appropriate way.</p>



Respecting First Nations Peoples: For Aboriginal, Torres Strait Islander or other First Peoples. Services should be culturally affirming for Aboriginal and Torres Strait Islander and other First Peoples, built on an acknowledgement 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.

Considerations	Examples/Responses
<p>This might look like...</p>	<p>The practitioner will build a relationship with my child, myself, and our broader network (if appropriate) to understand family structures and cultural background, including any languages that may be spoken at home.</p> <p>The practitioner will build a relationship to establish our understanding of autism, while acknowledging the various perceptions of disability more broadly within First Nations communities.</p> <p>The practitioner will listen without judgement when I share memories and past experiences about my child, to ensure I feel safe and respected.</p>
<p>Prompts and examples to consider...</p>	<ul style="list-style-type: none"> • Has my practitioner supported other First Nations children and families? • Do I feel comfortable involving other family members in my child's assessment and diagnostic process? • What do I imagine my child's future looks like if they're living their best life? How might this assessment and diagnostic process help my child to achieve that future?
<p>How important is this principle to you in experiencing a successful diagnostic process?</p>	<p><input type="checkbox"/> Extremely important</p> <p><input type="checkbox"/> Very important</p> <p><input type="checkbox"/> Moderately important</p> <p><input type="checkbox"/> Slightly important</p> <p><input type="checkbox"/> Not at all important</p> <p><input type="checkbox"/> Not applicable</p>
<p>For this principle to be achieved for my family, it will look / sound / feel like...</p>	<p>I will hear the practitioner asking respectful questions about my child's past, checking in on their wellbeing, and being sensitive to potential triggers and trauma.</p> <p>I will have an opportunity to ask questions, as well as to have questions asked of me. I will have time to reflect on questions I might have and can ask them at another time or have a way to ask</p>

	<p>questions via email or text in case they don't occur to me 'in the moment' at an appointment.</p> <p>I will feel comfortable and safe, without any feelings of judgement regarding my child's upbringing and experiences.</p> <p>I want to feel that our family's unique and personal journey, and connection to culture, country and values are acknowledged as core to my child's being.</p>
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Neurodiversity-affirming: Assessment and diagnosis should be neurodiversity-affirming, embracing each client’s unique understanding of themselves, other people, and the world around them.

Considerations	Examples/Responses
<p>This might look like...</p>	<p>The practitioner explains what neurodiversity is, and how autism fits as a neurotype within a neurodiversity-affirming approach.</p> <p>The practitioner does not use deficit-based or stigmatising language and explains the assessment and diagnostic process in ways that affirm and validate my child’s experiences.</p>
<p>Prompts and examples to consider...</p>	<ul style="list-style-type: none"> • How do I feel most comfortable talking about autism? If the practitioner explains autism as a difference rather than a deficit, how does that feel? • How does the practitioner understand ‘neurodiversity-affirming’ practice? What principles do they apply within this approach? What is my understanding of this approach? Are there differences between the practitioner’s understanding and my own?
<p>How important is this principle to you in experiencing a successful diagnostic process?</p>	<p><input type="checkbox"/> Extremely important</p> <p><input type="checkbox"/> Very important</p> <p><input type="checkbox"/> Moderately important</p> <p><input type="checkbox"/> Slightly important</p> <p><input type="checkbox"/> Not at all important</p> <p><input type="checkbox"/> Not applicable</p>
<p>For this principle to be achieved for my family, it will look / sound / feel like...</p>	<p>For example, I might hear the practitioner re-frame or ‘translate’ the diagnostic criteria into neuro-affirming language that validates my child’s experiences as different, not deficient.</p>



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.

Considerations	Examples/Responses
<p>This might look like...</p>	<p>The practitioner is willing to share their training and experience in the assessment and diagnosis of autism (and other co-occurring conditions), including any training led by autistic people and experts with lived experience of autism.</p> <p>The practitioner should be able to answer any questions I have about my child’s autistic identity with knowledge and confidence. This might include questions about neurodiversity/neurodiversity-affirming practice, evidence-based practice, or common co-occurring conditions.</p>
<p>Prompts and examples to consider...</p>	<ul style="list-style-type: none"> • What kinds of knowledge or information do I want from the practitioner? What is most important for me to know or find out about? • What information do I expect the practitioner to know for me to feel confident in their competence? • What characteristics, circumstances, and/or contexts does my child bring to the assessment that might require the practitioner to have specialised knowledge?
<p>How important is this principle to you in experiencing a successful diagnostic process?</p>	<p><input type="checkbox"/> Extremely important</p> <p><input type="checkbox"/> Very important</p> <p><input type="checkbox"/> Moderately important</p> <p><input type="checkbox"/> Slightly important</p> <p><input type="checkbox"/> Not at all important</p> <p><input type="checkbox"/> Not applicable</p>
<p>For this principle to be achieved for my family, it will look / sound / feel like...</p>	<p>For example, I might hear the practitioner speak knowledgeably about a range of co-occurring conditions (such as, eating disorders, ADHD, hypermobility) and demonstrate an understanding of the complex and diverse presentations of autism.</p>



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.

Considerations	Examples/Responses
This might look like...	I am given clear information about waiting lists and the costs involved in the assessment and diagnostic process, and any alternatives if these are not acceptable or feasible for me and my child.
Prompts and examples to consider...	<ul style="list-style-type: none"> • How long am I prepared to wait for my preferred practitioner? • How much am I able to pay for my preferred practitioner? • What alternatives are available to me if my preferred practitioner is not within my time or resource budget?
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	For example, I will be given clear guidance in advance of all costs involved, including for a full assessment and diagnostic report, and for all appointments. I will be empowered with clear and accurate information and alternatives to pursue if required.




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

Considerations	Examples/Responses
<p>This might look like...</p>	<p>The practitioner asks me for permission to contact my child's existing formal supports, whose expertise in my child's life and experiences may be beneficial. I have the right not to provide such contacts if I wish.</p> <p>The practitioner provides specific recommendations for types of formal supports that might be beneficial to my child at any stage within the assessment and diagnostic process, and in line with what is helpful to me and my child.</p>
<p>Prompts and examples to consider...</p>	<ul style="list-style-type: none"> • Who currently exists in my child's team that might be able to provide a meaningful contribution to the process? For example, psychologist, psychiatrist, GP, occupational therapist, speech therapist, teacher. • Am I interested in developing a formal support team that is responsive to my child's needs as indicated through the assessment and diagnostic process? How can the practitioner help me to develop this plan for support?
<p>How important is this principle to you in experiencing a successful diagnostic process?</p>	<p><input type="checkbox"/> Extremely important</p> <p><input type="checkbox"/> Very important</p> <p><input type="checkbox"/> Moderately important</p> <p><input type="checkbox"/> Slightly important</p> <p><input type="checkbox"/> Not at all important</p> <p><input type="checkbox"/> Not applicable</p>
<p>For this principle to be achieved for my family, it will look / sound / feel like...</p>	<p>For example, I will receive information from the practitioner about the various types of supports available to my child, including funding supports, what these supports do for and offer to my child, and how different supports will help my child to thrive and work towards their aspirations.</p>

Guiding Principles questionnaire template

Fill in your own thoughts using this blank **Guiding Principles questionnaire template**. You can refer to the examples and prompts provided in the example questionnaire on pages 18 to 29.

 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.	
Considerations	Responses
This might look like...	
Prompts and examples to consider...	
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	



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.

Considerations	Responses
This might look like...	
Prompts and examples to consider...	
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	



Holistic: Assessments 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.

Considerations	Responses
This might look like...	
Prompts and examples to consider...	
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	



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.

Considerations	Responses
This might look like...	
Prompts and examples to consider...	
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	



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.

Considerations	Responses
This might look like...	
Prompts and examples to consider...	
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	



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.

Considerations	Responses
This might look like...	
Prompts and examples to consider...	
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	



Respecting First Nations Peoples: For Aboriginal, Torres Strait Islander or other First Peoples. Services should be culturally affirming for Aboriginal and Torres Strait Islander and other First Peoples, built on an acknowledgement 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.

Considerations	Responses
This might look like...	
Prompts and examples to consider...	
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	



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

Considerations	Responses
This might look like...	
Prompts and examples to consider...	
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	



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.

Considerations	Responses
This might look like...	
Prompts and examples to consider...	
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	



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.

Considerations	Responses
This might look like...	
Prompts and examples to consider...	
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	



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

Considerations	Responses
This might look like...	
Prompts and examples to consider...	
How important is this principle to you in experiencing a successful diagnostic process?	<input type="checkbox"/> Extremely important <input type="checkbox"/> Very important <input type="checkbox"/> Moderately important <input type="checkbox"/> Slightly important <input type="checkbox"/> Not at all important <input type="checkbox"/> Not applicable
For this principle to be achieved for my family, it will look / sound / feel like...	

Notes

Take notes in the space provided below. Your notes may help guide your discussion with the practitioner when you meet with them next, and ensure your expectations, questions and concerns are being addressed.

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

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