



The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia: National guideline summary & recommendations

Draft version for community consultation

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There is currently no consistent process across Australia for how an individual is assessed for a diagnosis of autism spectrum disorder (ASD). This inconsistency has led to uneven service provision across the Australian states and territories, along with confusion within the community about the diagnostic process. The aim of this guideline is to define a diagnostic assessment process that is acceptable to consumers, feasible to conduct, effective in delivering accurate diagnostic decisions, and comprehensive in guiding future clinical management.

The guideline was developed through a 12-month process that involved a series of research and consultative activities, including a workshop in each state of Australia. The development process was led by a small team of senior clinicians and researchers, along with a Steering Committee made up of representatives from the major professional and consumer organisations. The guideline was developed and is published by Autism CRC Ltd (www.autismcrc.com.au). The authors and Autism CRC acknowledge the financial support of the National Disability Insurance Agency.

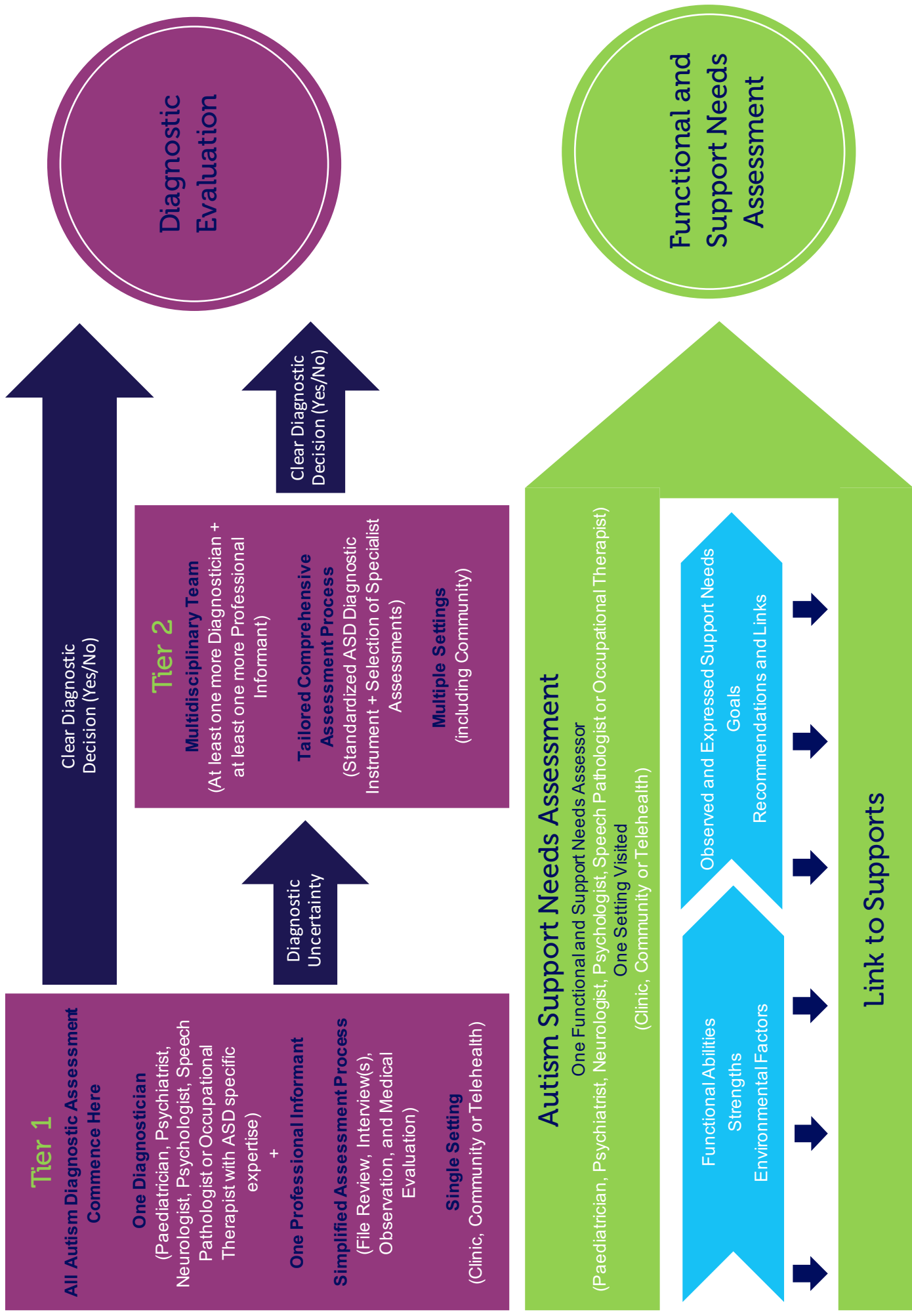
The guideline outlines a step-by-step process for conducting an ASD assessment from the time of referral until the assessment results are shared in a written report. The 76 recommendations included in the guideline were based on the strength of identified research evidence and feedback from the consultative activities. Each recommendation has a corresponding 'evidence table' that presents the research evidence and consultative feedback on which the recommendation was based.

Key aspects of the guideline include:

- 1 An 'ASD assessment' being defined as both a Diagnostic Evaluation (Does the individual meet criteria for ASD?) and a Functional and Support Needs Assessment (What are the key strengths and challenges that inform future clinical management?).
- 2 A 'tiered process' of assessment, which will facilitate accurate and efficient assessment for the full range of ASD presentations.
- 3 Health professional(s) performing the Diagnostic Evaluation (the 'diagnostician') must have both qualifications in a defined clinical profession, and defined knowledge and experience in working with individuals with ASD.
- 4 A description of the settings in which the behaviours of the individual being assessed must be observed.
- 5 Information about how a Diagnostic Evaluation can be adapted for individuals in regional or remote location.
- 6 The description of a range of additional considerations that are known to have a bearing on the ASD Diagnostic Evaluation, including the age, gender, intellectual capacity and cultural/linguistic background of the individual being assessed, as well as differential diagnoses and co-occurring conditions.
- 7 Resources to aid health professionals, including decision-making guides, templates for written reports completed as part of the ASD assessment, as well as case studies to demonstrate the proposed ASD assessment process.
- 8 An accompanying technical report provides detailed information on the guideline development process and the evidence supporting the recommendations made in this guideline.

This use of this guideline will ensure that minimum standards for ASD diagnosis are met, and that every individual is provided an optimal and comprehensive assessment to guide future clinical management.

Figure 1. Overview of the ASD assessment structure



1 ASD ASSESSMENT GUIDING PRINCIPLES

1.1 Individual and Family Centred

The ASD assessment process must follow an individual and family centred approach, by which assessment professionals collaborate with individuals and their families to identify the unique needs, strengths and contexts of the person undergoing assessment and their broader family unit. [Evidence Table 1]

1.2 Holistic Framework

The ASD assessment process must follow a holistic framework, where an individual is evaluated in the context of personal, activity and environmental contexts (for example, the World Health Organization's International Classification of Functioning, Disability and Health). [Evidence Table 2]

1.3 Strengths Focused

The ASD assessment process must follow a strengths-focused approach, in which identifying the strengths, skills, interests, resources and support systems of the individual is recognised as being as important as identifying limitations. [Evidence Table 3]

1.4 Evidence Based

The ASD assessment process must follow an evidence-based approach, where decisions whilst planning and undertaking the assessment are based on a review of the best available research evidence. [Evidence Table 4]

2 ASD ASSESSMENT SCOPE

2.1 Content of an ASD Assessment

The ASD assessment process should include both:

- 1 A Diagnostic Evaluation; and
- 2 A Functional and Support Needs Assessment. [Evidence Table 5]

2.2 Coordination of an ASD Assessment

The ASD assessment process should be coordinated by a central contact person from the point of referral until the time when ASD assessment findings have been communicated to the individual and/or their caregiver(s). [Evidence Table 6]

3 ASD ASSESSMENT ROLES

3.1 Referrer

A Referrer may be a Consumer or professional with an adequate awareness of ASD and typical development to initiate the ASD assessment process. [Evidence Table 7]

3.2 Coordinator

A Coordinator should be a medical, allied health or administrative professional with appropriate knowledge and expertise of the ASD assessment process. [Evidence Table 8]

3.3 Diagnostician

Paediatricians who are registered with the Medical Board of Australia and a Fellow of the Royal Australasian College of Physicians - Paediatrics & Child Health Division are eligible to be a Diagnostician. [Evidence Table 9]

Psychiatrists who are registered with the Medical Board of Australia and a Fellow of the Royal Australian and New Zealand College of Psychiatrists are eligible to be a Diagnostician. [Evidence Table 10]

Neurologists who are registered with the Medical Board of Australia and a Fellow of the Royal Australasian College of Physicians (with accreditation to practice as a Neurologist) are eligible to be a Diagnostician. [Evidence Table 11]

Registered psychologists who are registered with the Psychology Board of Australia are eligible to be a Diagnostician. [Evidence Table 12]

Speech pathologists who are a Certified Practicing Member of Speech Pathology Australia are eligible to be a Diagnostician. [Evidence Table 13]

Occupational therapists who are registered with the Occupational Therapy Board of Australia and the Better Access to Mental Health program are eligible to be a Diagnostician. [Evidence Table 14]

Diagnosticians must have demonstrated ASD specific expertise in all of the following areas:

- Typical and atypical development across the age range assessed in their practice;
- ASD symptom presentation across all developmental stages in which they practice;
- ASD symptom presentation among male, female, and where applicable, gender diverse individuals;
- Symptoms associated with common co-morbid and differential diagnosis conditions;
- Current international ASD diagnostic criteria (e.g. DSM-5 and/or ICD-10);
- Administering ASD diagnostic assessments (all prerequisites for using the instrument in clinical practice must be met);
- Administering other standardised assessments utilised within the Diagnostic Evaluation (all prerequisites for using the instrument in clinical practice must be met);
- Clinical reasoning in weighing evidence, integrating findings, reaching assessment conclusions and making diagnostic decisions;

- Clinical report writing; and
- Communicating with autistic individuals and their caregivers. [Evidence Table 15]

Diagnosticians must obtain ASD specific expertise through all four of the following learning approaches:

- 1 Demonstrating at least four years fulltime equivalent of postgraduate experience that is directly relevant to ASD Diagnostic Evaluations, obtained through university qualifications, formal training programs and/or formally supervised work experience;
- 2 Observing peers conducting ASD Diagnostic Evaluations and making diagnostic decisions;
- 3 Receiving peer supervision and feedback upon observation of ASD Diagnostic Evaluations and diagnostic decisions; and
- 4 Receiving peer mentoring in ASD diagnoses. [Evidence Table 16]

Diagnosticians must maintain their ASD specific expertise, achieved through peer learning, formal training courses and/or further qualifications. [Evidence Table 17]

3.4 Functional and Support Needs Assessor

Paediatricians who are registered with the Medical Board of Australia and a Fellow of the Royal Australasian College of Physicians - Paediatrics & Child Health Division, or who are undertaking training to become a Fellow of this Division, are eligible to be a Functional and Support Needs Assessor. [Evidence Table 18]

Psychiatrists who are registered with the Medical Board of Australia and a Fellow of the Royal Australian and New Zealand College of Psychiatrists, or who are training to become a Fellow of this College, are eligible to be a Functional and Support Needs Assessor. [Evidence Table 19]

Neurologists who are registered with the Medical Board of Australia and a Fellow of the Royal Australasian College of Physicians (with accreditation to practice as a Neurologist), or undertaking training to become accredited to practice as a Neurologist, are eligible to be a Functional and Support Needs Assessor. [Evidence Table 20]

Registered psychologists who are registered with the Psychology Board of Australia are eligible to be a Functional and Support Needs Assessor. [Evidence Table 21]

Speech pathologists who are a Certified Practicing Member of Speech Pathology Australia are eligible to be a Functional and Support Needs Assessor. [Evidence Table 22]

Occupational therapists who are registered with the Occupational Therapy Board of Australia are eligible to be a Functional and Support Needs Assessor. [Evidence Table 23]

Functional and Support Needs Assessors must have current ASD specific knowledge and experience in all of the following areas:

- Typical and atypical development across the age range assessed in their practice;
- ASD symptom presentation across the developmental stages in which they are practicing;
- ASD symptom presentation among male, female, and where applicable, gender diverse individuals;
- Administering standardised functional assessments to identify the impact of ASD / comorbid condition symptoms on daily functioning and participation in age appropriate activities;
- Identifying individual strengths;
- Identifying environmental contexts, facilitators and barriers;
- Identifying and prioritising support needs;
- Identifying local supports available to meet the needs of autistic individuals and their caregivers;
- Clinical report writing; and
- Communicating with autistic individuals and their caregivers. [Evidence Table 24]

Functional and Support Needs Assessors may obtain and maintain this knowledge and experience through a combination of:

- University qualifications;
- Other formally assessed training;
- Non-assessed training;
- Peer learning; and/or
- Work experience. [Evidence Table 25]

Functional and Support Needs Assessors who administer standardised assessments must have current expert knowledge of, and experience in, administering the instrument. All qualifications and prerequisites for using the instrument in clinical practice must be met. [Evidence Table 26]

3.5 Professional Informant

A Professional Informant should be a medical, allied health or education professional (with a four year fulltime equivalent degree), who has current knowledge of typical and atypical development (obtained through a range of formal or informal learning approaches). [Evidence Table 27]

4 ASD ASSESSMENT SETTINGS

4.1 Multiple Settings

The ASD assessment should involve collection of information about an individual's behaviour in at least two settings relevant to the individual's daily life, ideally through direct observation by the Diagnostician, but also through secondary reports provided by the caregiver and/or Professional Informant(s). [Evidence Table 28]

4.2 Types of Settings

A clinic setting is an appropriate, but not essential, venue for an ASD assessment. However, additional information must also be obtained about an individual's behaviour in a community setting relevant to their daily life. [Evidence Table 29]

During an ASD assessment, information must be obtained about an individual's behaviour in community settings relevant to their daily life [Evidence Table 30]

Information for an ASD assessment may be collected in a telehealth setting only, without meeting face-to-face with the Consumer in a clinic or community setting, where regional / remote location or travel restrictions makes face-to-face assessment very difficult. [Evidence Table 31]

When information for an ASD assessment is collected through video conferencing and/or recordings only, at least one Diagnostician should obtain information from a Professional Informant within the local community who has met face-to-face with the individual undergoing assessment. [Evidence Table 32]

5 INITIATING AN ASD ASSESSMENT

5.1 Recognition of Signs and Symptoms of ASD

When professionals are evaluating whether a referral for an ASD assessment is required, they should use clinical judgement to weigh the strength of evidence for ASD signs and symptoms. [Evidence Table 33].

5.2 Making a Referral for an ASD Assessment

A Referral Form for an ASD assessment should include a clear rationale that an ASD assessment is appropriate and provide the defined, prerequisite information to efficiently commence the process. [Evidence Table 34]

5.3 Acting on a Referral for an ASD Assessment

Upon receipt of the Referral Form, the Coordinator becomes the key contact for the Consumer during the ASD assessment process and takes primary responsibility for providing the Consumer with sufficient information, collating documents and managing appointments. [Evidence Table 35]

6 DIAGNOSTIC EVALUATION

6.1 Diagnostic Criteria

Diagnosticians should use the current versions of either of the following international diagnostic manuals to make diagnostic decisions in relation to ASD:

- Diagnostic and Statistical Manual of Mental Disorders
- International Statistical Classification of Diseases and Related Health Problems. [Evidence Table 36]

6.2 Diagnostic Evaluation Structure

The Diagnostic Evaluation process for all individuals should commence with a Tier 1 Diagnostic Evaluation. This is a simplified assessment process to determine whether an ASD diagnosis can be confirmed or ruled out with certainty. If diagnostic certainty cannot be achieved, the individual should continue on to a Tier 2 Diagnostic Evaluation for more detailed assessment. [Evidence Table 37]

6.3 Tier 1 Diagnostic Evaluation

A Tier 1 Diagnostic Evaluation should be conducted by one Diagnostician, with input from at least one Professional Informant from a different professional discipline or specialty. [Evidence Table 38]

A Tier 1 Diagnostic Evaluation must include direct observation of the individual being assessed for ASD in either a clinical, community or telehealth setting. [Evidence Table 39]

Information about the individual's participation in at least two relevant community settings must also be obtained from the Consumer and/or Professional Informant. [Evidence Table 40]

A Tier 1 Diagnostic Evaluation must involve the collection of information on the following topics:

- Medical and health history;
- Family history;
- Developmental history;
- ASD specific symptoms; and
- Other relevant behaviours and/or symptoms. [Evidence Table 41]

A Tier 1 Diagnostic Evaluation must involve the collection of information through all of the following means:

- File review;
- Interview with* and/or observation of the individual being assessed for ASD;
- Interview with a caregiver*;
- Medical evaluation of the individual being assessed for ASD; and
- Discussion with the Professional Informant(s).
- If appropriate based on age and communication abilities [Evidence Table 42]

Diagnostic decisions made by the Diagnostician at Tier 1 must be made by:

- Taking into account all information collected in the Tier 1 Diagnostic Evaluation;
- Integrating and weighing the available evidence against each diagnostic criterion (according to the current version of the DSM or ICD); and
- Testing alternative explanations for symptoms that may warrant differential or co-occurring diagnosis or alternative clinical pathways. [Evidence Table 43]

6.4 Tier 2 Diagnostic Evaluation

A Tier 2 Diagnostic Evaluation should be conducted by at least two Diagnosticians, with input from at least two Professional Informants, where professionals are selected on the basis of need and should come from different professional disciplines or specialties. [Evidence Table 44]

A Tier 2 Diagnostic Evaluation must include direct observation of the individual being assessed for ASD in two or more settings, where at least one is a community setting. These direct observations can be made by one or more Diagnosticians. [Evidence Table 45]

Information about the individual's participation in all relevant community settings must also be obtained during a Tier 2 Diagnostic Evaluation from the Consumer and/or Professional Informant. [Evidence Table 46]

Standardised ASD diagnostic tools should be used as a helpful complement to clinical decision making in Tier 2 Diagnostic Evaluations, but should not be used as a substitute for the clinical judgment of Diagnosticians. [Evidence Table 47]

An individually tailored selection of standardised instruments and non-standardised data collection tools should be conducted in Tier 2 Diagnostic Evaluations to address aspects where diagnostic certainty is lacking. [Evidence Table 48]

A Tier 2 diagnostic decision must be made by consensus among all Diagnosticians through:

- Taking into account all information collected in the Tier 1 and Tier 2 Diagnostic Evaluations;
- Integrating and weighing the available evidence against each diagnostic criteria (according to the current version of the DSM or ICD); and
- Testing alternative explanations for symptoms that may warrant differential or co-occurring diagnosis or alternative clinical pathways. [Evidence Table 49]

Where consensus cannot initially be achieved by the Diagnosticians, further information should be obtained to supply sufficient evidence to inform the final decision regarding an ASD diagnosis. [Evidence Table 50]

7 FUNCTIONAL AND SUPPORT NEEDS ASSESSMENT

A Functional and Support Needs Assessment is a core component of an ASD assessment, is to be completed at any time throughout the assessment process, and is designed to identify functional abilities and support needs, and to link Consumers to appropriate support services. [Evidence Table 51]

7.1 Functional Assessment

A Functional Assessment is conducted by at least one Functional and Support Needs Assessor, with input from Diagnosticians and Professional Informants involved in the Diagnostic Evaluation. [Evidence Table 52]

Information about the individual's functional abilities in all relevant community settings must be obtained during a Functional Assessment from the Consumer and/or Professional Informant. [Evidence Table 53]

The Functional Assessment should commence with a standardised tool to determine the individual's ability to independently perform everyday tasks. [Evidence Table 54]

The Functional Assessment should determine the individual's activity related and character strengths. [Evidence Table 55]

The Functional Assessment should explore how the individual's current environments impact on their functioning in a positive and negative way. [Evidence Table 56]

7.2 Support Needs Assessment

A Support Needs Assessment is conducted by at least one Functional and Support Needs Assessor, with input from Diagnosticians and Professional Informants involved in the Diagnostic Evaluation. [Evidence Table 57]

Information about the individual's support needs in all relevant community settings must be obtained during a Support Needs Assessment from the Consumer and/or Professional Informant. [Evidence Table 58]

The Support Needs Assessment should identify and prioritise observed and expressed support needs, and then develop related goals. [Evidence Table 59]

The Support Needs Assessment should involve the formulation of recommendations (with associated referrals if required) to address prioritised support needs. [Evidence Table 60]

7.3 Repeated Assessment

The Functional and Support Needs Assessment process should be repeated throughout the individual's life to ensure that changes to functional status and support needs are identified and acted upon in a timely manner. [Evidence Table 61]

8 SHARING ASD ASSESSMENT FINDINGS

8.1 Communication Style

Findings from the ASD assessment should be communicated to the Consumer in a comprehensive and understandable way through both a face-to-face meeting (or via a telehealth setting) and written-report. This should occur within three months of the first assessment appointment. [Evidence Table 62]

8.2 Content of Communication

The following information should be conveyed during the meeting(s) and recorded in the written report(s):

- Clear confirmation of the diagnostic outcome (i.e. individual does or does not meet criteria for ASD);
- ASD diagnostic criteria utilised (e.g. DSM-5 or ICD-10);
- Evidence that supports the presence or absence of each ASD diagnostic criteria;
- Assessments conducted (e.g. name of instrument, administering professional, findings, implications);
- Co-occurring conditions identified, diagnosed or requiring further investigation;
- Current functional status and potential functional status with supports;
- Activity related and character strengths;
- Environmental facilitators and barriers;
- Highest priority support needs of the individual (and their caregivers, if appropriate) and related goals;
- Suggested time frame for reassessment of functional and support needs;

- Recommendations with sufficient details for the Consumer to action for:
 - Further assessments if required;
 - Informal and formal supports required; and
- Declaration by Diagnostician(s) and Functional and Support Needs Assessor that the ASD assessment was conducted according to this guideline; [Evidence Table 63]

9 IMPORTANT CONSIDERATIONS

9.1 Age

All professionals involved in an ASD assessment should consider the individual's behavioural presentation and needs in comparison to other individuals of the same age. [Evidence Table 64]

9.2 Intellectual and / or Communication Capacity

When conducting an ASD assessment, cognitive/intellectual abilities and verbal language level should be considered when choosing standardised assessments and determining the individual's ability to provide valid consent. [Evidence Table 65]

9.3 Gender

All professionals involved in an ASD assessment need to consider the individual's behavioural presentation and needs in comparison to other individuals of the same gender. [Evidence Table 66]

All professionals involved in an ASD assessment should have a good understanding of gender diversity, and its potential impact on the individual's behavioural presentation and needs [Evidence Table 67]

9.4 Culturally and Linguistically Diverse (CALD) Backgrounds

All professionals involved in an ASD assessment with an individual from a different racial or ethnic background, including Aboriginal peoples, should first obtain a good understanding about the cultural factors relevant to the individual and their caregivers that may guide or influence the ASD assessment process. [Evidence Table 68]

Community members should be allowed to provide cultural and/or language support to a Consumer during the ASD assessment if this is requested or identified as potentially beneficial. [Evidence Table 69]

All professionals involved in an ASD assessment with an individual from a non-English speaking background (including those who speak in an Aboriginal language), should make appropriate educational material available in a language appropriate for the individual and/or caregiver to enhance understanding of ASD and the support services they may be eligible for. [Evidence Table 70]

In the assessment of ASD in Aboriginal peoples, the role of the family, extended family and community should be acknowledged and empowered by identifying attitudes and beliefs that the individual and family have surrounding ASD. [Evidence Table 71]

When an ASD assessment is being conducted with Aboriginal individuals, Aboriginal Health Workers should be involved in this process from the receipt of referral through to the communication of assessment findings, and connection of the family to support services. [Evidence Table 72]

9.5 Regional or Remote Location

In circumstances where a Diagnostician with the prerequisite professional background and ASD specific expertise is not present in the local community, a partnership between local practitioners and Diagnostician(s) in another location should be facilitated through telehealth methods. [Evidence Table 73]

Prior to conducting an ASD assessment, professionals within the multidisciplinary assessment team must have a good understanding of the support services available for the individuals in their local or regional community. [Evidence Table 74]

9.6 Differential Diagnosis and Co-occurring Conditions

Diagnosticians must be highly familiar with the full range of potential differential diagnoses for ASD. If a particular Diagnostician does not have the clinical qualifications or expertise to adequately evaluate a potential differential diagnosis for a given individual, then that individual should be referred to a professional who does have this expertise. [Evidence Table 75]

Diagnosticians must be highly familiar with the full range of conditions that commonly co-occur with ASD. If a particular Diagnostician does not have the clinical qualifications or expertise to adequately evaluate a potential co-occurring condition for a given individual, then that individual should be referred to a professional who does have this expertise. [Evidence Table 76]

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"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."

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