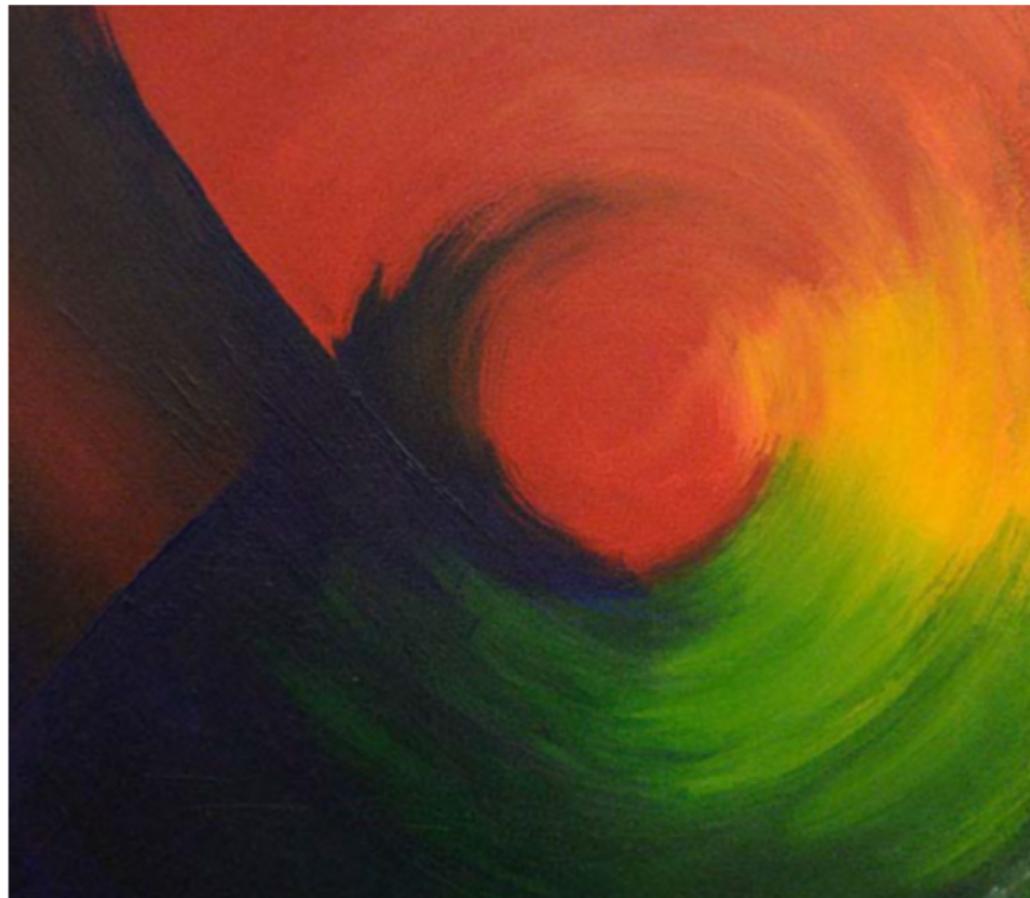




# The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia: A national guideline

**Draft version for community consultation**

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September 2017

The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia: A national guideline.

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### **September 2017**

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# CONTENTS

1	Acknowledgements.....	1
2	Foreword.....	2
3	Overview.....	4
3.1	Purpose .....	4
3.2	Definition of ASD .....	4
3.3	Diagnostic Criteria for ASD .....	4
3.4	Scope of the Guideline Development Process .....	5
3.4.1	Steering Committee .....	5
3.4.2	Literature Review .....	5
3.4.3	Community Consultation.....	6
3.4.4	Evidence Review .....	7
3.5	Instructions for Using this Guideline.....	8
4	ASD Assessment Guiding Principles.....	10
4.1	Individual and Family Centred.....	10
4.2	Holistic Framework .....	10
4.3	Strengths Focused.....	11
4.4	Evidence Based.....	11
5	ASD Assessment Scope.....	12
5.1	Content of an ASD Assessment.....	12
5.2	Coordination of an ASD Assessment .....	12
6	ASD Assessment Roles .....	13
6.1	Consumer .....	13
6.2	Referrer .....	13
6.3	Coordinator.....	14
6.3.1	Professional Discipline.....	14
6.3.2	ASD Specific Expertise .....	14
6.4	Diagnostician .....	15
6.4.1	Professional Discipline.....	15

6.4.2	ASD Specific Expertise .....	16
6.5	Functional and Support Needs Assessor .....	20
6.5.1	Professional Discipline .....	20
6.5.2	ASD Specific Expertise .....	21
6.6	Professional Informant .....	22
6.6.1	Professional Discipline .....	22
6.6.2	ASD Specific Expertise .....	23
7	ASD Assessment Settings .....	24
7.1	Multiple Settings .....	24
7.2	Types of Settings .....	24
7.2.1	Clinic Setting.....	24
7.2.2	Community Setting.....	25
7.2.3	Telehealth Setting.....	25
8	Initiating an ASD Assessment.....	27
8.1	Recognition of Signs and Symptoms of ASD .....	27
8.1.1	Consumer and Community Observations.....	27
8.1.2	Evidence of Signs and Symptoms.....	27
8.2	Making a Referral for an ASD Assessment .....	30
8.3	Acting on a Referral for an ASD Assessment.....	31
9	Diagnostic Evaluation .....	33
9.1	Purpose .....	33
9.2	Diagnostic Criteria.....	33
9.3	Diagnostic Evaluation Structure .....	35
9.4	Tier 1 Diagnostic Evaluation .....	35
9.4.1	Professional Involvement.....	35
9.4.2	Settings.....	36
9.4.3	Information Collection .....	36
9.4.4	Diagnostic Decision Making.....	38
9.5	Tier 2 Diagnostic Evaluation .....	41
9.5.1	Professional Involvement.....	41
9.5.2	Settings.....	41

9.5.3	Information Collection - Standardised ASD Diagnostic Tool.....	44
9.5.4	Information Collection - Specialist Assessments .....	45
9.5.5	Diagnostic Decision Making .....	46
10	Functional and Support Needs Assessment .....	48
10.1	Purpose .....	48
10.2	Functional and Support Needs Assessment Structure .....	48
10.3	Functional Assessment.....	49
10.3.1	Professional Involvement.....	49
10.3.2	Settings.....	49
10.3.3	Information Collection .....	49
10.4	Support Needs Assessment.....	53
10.4.1	Professional Involvement.....	53
10.4.2	Settings.....	53
10.4.3	Information Collection .....	53
10.5	Repeated Assessment.....	55
11	Sharing ASD Assessment Findings .....	56
11.1	Communication Style .....	56
11.2	Content of Communication.....	56
12	Important Considerations .....	58
12.1	Age .....	58
12.2	Intellectual and / or Communication Capacity .....	64
12.3	Gender.....	65
12.4	Culturally and Linguistically Diverse (CALD) Backgrounds.....	66
12.5	Regional or Remote Location.....	68
12.6	Differential Diagnosis and Co-occurring Conditions .....	69
12.6.1	Differential Diagnosis .....	70
12.6.2	Co-occurring Conditions .....	71
13	References.....	73

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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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## 2 FOREWORD

Diagnosis of autism spectrum disorder (ASD) has long been a challenging issue. Because there is currently no established biological marker for all autistic individuals, ‘gold standard’ diagnosis is presently a best estimate clinical judgement based on the behavioural presentation of the individual [1-3]. However, the variability in ASD symptoms and the considerable behavioural overlap with other developmental conditions means that ASD diagnosis is not a straightforward clinical task. While diagnostic manuals such as the Diagnostic and Statistical Manual for Mental Disorders (DSM) and the International Classification of Diseases (ICD) provide clear behavioural criteria for diagnoses, the appraisal of these behaviours is an inherently subjective task that relies heavily on clinician experience and skill.

This task of providing accurate ASD diagnoses in Australia is complicated further by significant variability between states and territories in the composition of the clinical diagnostic team. While some states require an ASD diagnosis to be made through consensus of an experienced multidisciplinary assessment team of a paediatrician / psychiatrist, psychologist and speech pathologist, other states have less stringent criteria [3-5]. Different diagnostic standards can also apply between the health, education and disability public services offered by each state / territory and federally, such that a diagnostic decision that is recognised by health or disability services early in life, may not be recognised by the education system when the child reaches school age.

In 2014, a review of ASD diagnostic practices in Australia was jointly commissioned by the Cooperative Research Centre for Living with Autism (Autism CRC) and the Commonwealth Department of Social Services [3]. A key finding from this report was the considerable variability between states in diagnostic practices, including the quality and quantity of assessments administered, the professionals involved, and the required experience of these professionals. The report concluded that this variability is highly likely to have contributed to uneven service provision across the states / territories and confusion amongst consumers undergoing diagnostic assessment.

The main recommendation of the report was:

“Adopting a minimum national standard for ASD diagnosis across Australia would improve diagnostic practices and consistency across the country, and ensure that future diagnostic assessments are in keeping with best practice guidelines.”

The development and implementation of a consistent, national guideline for ASD diagnosis in Australia will provide the community with greater equity in access to a rigorous and comprehensive assessment, transparency in the diagnostic and decision-making processes, and confidence in the accuracy and reliability of diagnostic decisions.

In June 2016, under the terms of a Collaboration Agreement between the two, the National Disability Insurance Agency commissioned Autism CRC to develop Australia’s first national guideline for ASD diagnosis in Australia. Professor Andrew Whitehouse was requested to Chair this process, in collaboration with a Research Executive team comprising Dr Kiah Evans, Professor Valsamma Eapen, Clinical Associate Professor John Wray and Professor Margot Prior.

This Research Executive team was set the task of developing a guideline that defines an assessment process that is comprehensive in scope, acceptable to consumers, feasible for clinicians to administer, and effective and efficient in delivering accurate diagnostic

outcomes. The 12-month process conducted by the Research Executive team in developing the guideline comprised a thorough desktop review of existing research evidence and extensive consultation with key stakeholders.

This document presents Australia's first national guideline for the assessment of ASD, which outlines processes for both diagnostic decision-making and the comprehensive assessment of individual support needs. 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. This process is supported by the inclusion of clinical algorithms, case studies and templates. An accompanying technical report provides detailed information on the guideline development process and the evidence supporting the recommendations made in this guideline.

We note that identity-first language (e.g. autistic children and adults) is the preferred language of many people on the autism spectrum and their parents [6]. We therefore use this terminology to describe the children and families in this guideline.

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## 3 OVERVIEW

### 3.1 Purpose

This guideline was produced to support clinicians who undertake diagnostic assessments that may result in an ASD diagnosis. The guideline does not seek to reform or replace the ASD behaviours outlined in the DSM or ICD diagnostic manuals, but rather provides a framework that enables an effective and efficient appraisal of these behaviours.

The clinical presentation of ASD is complex and varies between individuals. In some individuals, the behavioural features of ASD are obvious – a so called ‘frank presentation’ [7] – and confirming a diagnosis is relatively straightforward. In other individuals, behavioural features can be more subtle and/or combined with additional clinical difficulties, making an accurate evaluation of those behaviours more difficult. A diagnostic guideline must describe a process that is both flexible enough to be tailored to an individual’s behavioural presentation, but also ensure that a comprehensive assessment is conducted with all individuals to guide their future clinical management.

This guideline has been developed through an evaluation of the current evidence base, as well as through a series of comprehensive community consultative activities. A series of associated documents provide detailed information on how these activities guided the recommendations made in this guideline.

### 3.2 Definition of ASD

Autism Spectrum Disorder (ASD) is the collective term for a group of neurodevelopmental disorders characterised by impairments in social interaction, verbal and nonverbal communication and by repetitive patterns of behaviour and restricted interests. The behavioural features that characterise ASD are often present before three years of age, but may also first become apparent during the school years or later in life. The developmental challenges and symptoms can vary widely in nature and severity between individuals, and also in the same individual over time, as well as being accompanied by mental and physical health problems.

### 3.3 Diagnostic Criteria for ASD

ASD is diagnosed when an individual displays a certain set of behaviours. There are two sets of diagnostic criteria commonly used throughout Australia and the world, and each uses different diagnostic terminology. The American Psychiatric Association publishes the Diagnostic and Statistical Manual of Mental Disorders (currently in its 5th edition - DSM-5), which uses the term ‘Autism Spectrum Disorder’. The World Health Organization publishes the International Classification of Diseases (currently in its 10th revision; ICD-10), which uses the terms ‘Childhood Autism’, ‘Atypical Autism’ and ‘Asperger Syndrome’. While this document will use the term ‘Autism Spectrum Disorder’ for simplicity, these guidelines are to be used for children referred for a diagnostic assessment that uses either the DSM-5 (Autism Spectrum Disorder) or ICD-10 (Childhood Autism, Atypical Autism and Asperger Syndrome) criteria.

## 3.4 Scope of the Guideline Development Process

The objective of this Research Executive team was to develop a guideline that:

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

In order to meet these objectives, the Research Executive team devised a set of research questions (Chapter 1 of the Technical Report). A series of literature reviews and community consultation activities were subsequently conducted over a 12-month period (September 2016 to August 2017) to ensure this guideline adhered to international best practice standards [8-12]. These activities are described in detail in the associated Technical Report (copy available on request), but in brief, these activities comprised the following:

### 3.4.1 Steering Committee

The national peak bodies of professions commonly involved in the diagnosis and management of autistic individuals were invited to provide a representative to a Steering Committee. The Steering Committee also included representatives from consumer organisations, including adults with a diagnosis of ASD. The Steering Committee members, and the national peak bodies they represent, are provided in Table 1 (with detailed information on their expertise and declared interests provided in Chapter 2 of the Technical Report). The Research Executive met with the Steering Committee via teleconference on four occasions throughout the 12-month period in which the guidelines were developed. During these meetings, the Steering Committee provided critical feedback on the work generated to date and shared their stakeholder group's perspective on the ASD assessment process.

### 3.4.2 Literature Review

An initial scoping review was conducted to map the breadth and depth of the available evidence on the ASD diagnostic process within similar cultures (Chapter 3 of the Technical Report). A series of systematic reviews were then conducted to determine the extent and quality of the existing published evidence (Chapter 3 of the Technical Report). This included systematic reviews of ASD diagnostic guidelines published in the Anglosphere (Australia, New Zealand, North America, and the British Isles), along with academic literature on the diagnostic accuracy of ASD diagnostic instruments, experiences of individuals, caregivers and practitioners of the ASD diagnostic process and factors influencing temporal outcomes during the completion of an ASD diagnostic assessment.

### 3.4.3 Community Consultation

Two open consultation processes were provided, where any individual living in Australia who was interested in providing input on important considerations during ASD assessment could participate. The first was a brief online submission portal completed by 238 individuals (Chapter 4 of the Technical Report), and the second was a series of eight workshops held in capital cities across Australia (including one workshop conducted via videoconference) and attended by 273 individuals (Chapter 5 of the Technical Report).

**Table 1. Steering Committee members**

<b>Stakeholder group</b>	<b>National Peak Body</b>	<b>Representative</b>
Autistic Individuals	Autistic Self Advocacy Network of Australia and New Zealand	Ms Jacky den Houting
Individuals with an Aboriginal or Torres Strait Islander background	First Peoples Disability Network Australia	Ms Dianne Brookes
Individuals and service providers living in a rural or remote area	National Rural Health Alliance	Dr Jo McCubbin
ASD specific service providers	Australian Autism Alliance	Mr Jon Martin
Parents and caregivers	Autism Awareness	Ms Nicole Rogerson
General practitioners	Royal Australian College of General Practitioners	A/Prof Bob Davis
Occupational therapists	Occupational Therapy Australia	Ms Susanne Nelson
Nurses	Australian Primary Health Care Nurses Association	Ms Jane Bollen
Paediatricians	The Royal Australasian College of Physicians - Paediatrics & Child Health Division	Dr Jacqueline Small

Psychiatrists	Royal Australian and New Zealand College of Psychiatrists	Prof Julian Trollor and Prof Valsamma Eapen
Psychologists	Australian Psychological Society	Dr Josephine Barbaro and Dr Janine Manjiviona
Speech pathologists	Speech Pathology Australia	Ms Robyn Stephen
Teachers	Australian Professional Teachers Association	Ms Helen Little

Three sets of targeted consultations were also undertaken, in which the perspectives of specific professional groups and consumers were elicited. First, consensus recommendations for ASD diagnosis were sought from a group of 77 medical, health and educational experts through a survey that adopted the Delphi method (Chapter 6 of the Technical Report). Second, the relative importance of different aspects of an ASD assessment was measured through a viewpoint survey with 12 autistic adolescents and adults, and 26 caregivers of autistic adolescents and adults (Chapter 7 of the Technical Report). Finally, the personal experience of undergoing an ASD diagnostic process was explored through individual interviews with 14 autistic adults (Chapter 8 of the Technical Report).

Strong support was expressed through each of these studies of the need for Australia to have a consistent national guideline for ASD diagnosis.

### 3.4.4 Evidence Review

Evidence from the literature reviews and community consultation have been summarised in an evidence table for each recommendation. The quality of the evidence and strength of the resulting recommendations was assessed using a modified approach based on the National Health & Medical Research Council approach (Table 2 and Chapter 9 of the Technical Report, [13]).

Symbol	Category	Evidence Source	Grade
CBR	Consensus Based Recommendation	Scholarly literature that was systematically identified and critically appraised.	1 Body of evidence is consistent across numerous evidence sources, and there is excellent support from experts for recommendation(s).
		Expert* opinion obtained through community	2 Body of evidence is mostly consistent across a number of evidence sources, and there is

		consultation and/or a systematic review of consensus guideline documents, where a systematic review of published research studies revealed an absence of quality evidence.	good support from experts for recommendation(s) with few caveats.
	3		Body of evidence is somewhat consistent but with some uncertainty, or limited to a small number of evidence sources, and there is satisfactory support from experts for recommendation(s) with some caveats.
	4		Body of evidence is inconsistent or lacking and there is poor support from experts for recommendation(s).
<p><i>* An “expert” includes someone with lived experience or professional expertise in relation to the ASD diagnostic process.</i></p>			

### 3.5 Instructions for Using this Guideline

This guideline has been developed to address the critical need for a consistent and comprehensive clinical protocol for ASD diagnosis in Australia. To make best use of the guideline, it is essential that clinicians familiarise themselves with the content enclosed in this document, and ensure that the requisite professional training is achieved and maintained in order to competently deliver these clinical services. While it was necessary to describe an overarching diagnostic framework that could apply to the full range of individuals that undergo ASD assessments, we reiterate the importance of tailoring the process to meet the needs of the individual consumer, including considering the broader neurodevelopmental features and environmental context of the individual.

Recommendations have been made throughout the document based on the evidence supporting clinical best practice collected during the guideline development process. The recommendations have been made in the context of the entire diagnostic process outlined in this document, and we strongly advise that these recommendations are taken as a whole, rather than in isolation of each other. Furthermore, it is critical that each recommendation is considered in light of the factors known to influence ASD symptom presentation, discussed in Section 12.

Embedded within the explanatory text in each chapter, are a series of recommendations formatted as in the example provided in Figure 1. The abbreviation ‘CBR – 1’ on the left of the recommendation indicates that it was formulated based on consensus evidence with a grade of one (the highest possible rating). The reference in square brackets following the recommendation indicates that the summary of literature review and/or community consultation evidence relating to this recommendation can be found in the third table of the Evidence Table document (copy available on request).

CBR - 1

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

***Figure 1. The above provides an example of how a recommendation is formatted within the guideline.***

# 4 ASD ASSESSMENT GUIDING PRINCIPLES

## 4.1 Individual and Family Centred

This principle is based around the key concept that the people who are most knowledgeable about the information required during an assessment of ASD are the individual undergoing assessment and their family members (most notably, caregivers and support people). The individual and/or family members are to be considered equal partners in the process of assessing ASD, and their needs, priorities and resources remain critical considerations at each step. This includes an acknowledgement of the diversity that exists within the community in terms of socioeconomic resources, education, cultural background, language spoken, and social-emotional factors that influence how an individual and/or family manages the process of an ASD assessment and the implications of the diagnostic decision. By placing the individual and family at the centre of the ASD assessment, the aim is to understand and build the capacity of each individual and family in order to meet their unique needs. This approach also encourages a degree of flexibility that enables the tailoring of the ASD assessment process to the individual's presentation.

CBR-1

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]

## 4.2 Holistic Framework

This principle is based around the key concept that an exclusive focus on the evaluation of ASD behaviours during the diagnostic process will fail to provide an adequate clinical appraisal of the individual. ASD is only one of a range of physical and mental health conditions that can affect an individual, and there are many instances in which atypical neurodevelopment may have significant functional impacts on an individual but not necessarily meet the diagnostic threshold for 'disorder'. Even when ASD is strongly suspected, diagnostic assessments must appraise the full range of clinical symptoms, and how these have emerged within the environmental context in which the individual lives. It is only by focusing first on the unique challenges and strengths of the individual that presents for an assessment, rather than on the matching of an individual to a diagnostic category, that the most appropriate and effective clinical management can be determined. The World Health Organization's International Classification of Functioning, Disability and Health (ICF) is used throughout this guideline as a holistic framework to describe the individual in terms of their underlying personal factors, body functions and structures, activities and participation, and environmental factors.

CBR-1

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]

### 4.3 Strengths Focused

This principle is based around the key concept that understanding the strengths of an individual and their family is as important for clinical management as identifying their challenges. By its very nature, an assessment for ASD requires an appraisal of the behavioural challenges of an individual. However, every individual being assessed will also have a range of behavioural and cognitive strengths, as well as resources within the broader family and environmental context in which they live. Assessment and identification of these strengths is critical to understanding the whole clinical profile of an individual, providing context to the limitations identified in the assessment, and determining the areas of functional need and potential.

CBR-1

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]

### 4.4 Evidence Based

This principle is based around the key concept that clinical management is most effective and safe when it is based on rigorous scientific evidence. Unlike medical conditions that are diagnosed based on clear biological observations, an ASD diagnosis is currently based on an evaluation of behaviours. While judgment of behaviour is an inherently subjective task, this task can and should be framed by the extensive evidence base regarding clinically-informed decision making for ASD. This includes the skills and experience of the diagnostician(s), the information collected to inform clinical judgment, and how this evidence is evaluated to form a diagnostic decision. The importance of using this evidence base to inform the diagnostic process cannot be overemphasised, and is at the heart of an accurate and ethical diagnostic guideline.

CBR-1

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]

# 5 ASD ASSESSMENT SCOPE

## 5.1 Content of an ASD Assessment

In its most literal form, a diagnostic assessment seeks to evaluate whether an individual meets defined criteria for a given health or medical condition. However, it is critical for the future clinical management of the individual being assessed to not just understand the presence or absence of ASD diagnostic behaviours, but also evaluate the functional and support needs of the individual and their caregivers. For this reason, the ASD assessment outlined in this guideline incorporates the dual processes of: (1) Diagnostic Evaluation and; (2) a Functional and Support Needs Assessment.

A Diagnostic Evaluation seeks to answer the question: *“Does the individual meet criteria for ASD?”*

The Functional and Support Needs Assessment aims to explore the question: *“What are the key strengths and challenges that inform future clinical management?”*

CBR-1

The ASD assessment process should include both:

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

## 5.2 Coordination of an ASD Assessment

Given that the assessment process involves the collection of information from multiple individuals across different settings, it is critical that there is coordination of the process by a central contact person. Centralised coordination involves having a single individual who collates the information collected from different individuals during the assessment process, and who takes responsibility for communicating progress through the assessment with the individual and/or their caregivers (6.3 for more details on the Coordinator role).

CBR-1

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]

## 6 ASD ASSESSMENT ROLES

The ASD assessment process commences when a Referrer provides a formal referral of a Consumer to health professionals eligible to conduct an ASD Assessment. The multidisciplinary assessment team involves a collaborative working relationship between medical, allied health, education and administrative professionals with relevant expertise in the ASD assessment process. This team comprises a Coordinator, Diagnostician(s), Functional and Support Needs Assessor(s) and Professional Informant(s).

### 6.1 Consumer

Consumer is an overarching term to describe an individual being assessed for ASD and any caregiver(s) or support people participating in the process. It is recognised that some individuals will participate in the process independently, whereas others will require assistance from a caregiver due to factors such as their age or communication/intellectual abilities. A caregiver or support person may include a parent, guardian, spouse, sibling, offspring or friend. Consumers are responsible for providing accurate and timely information to members of the multidisciplinary assessment team (i.e. Coordinator, Diagnosticians, Functional and Support Needs Assessors and Professional Informants).

CBR-1

The Consumer is an essential participant in an ASD assessment process, providing critical information that will guide diagnostic decision making. [Evidence Table 1]

### 6.2 Referrer

Referrers do not need any specific professional background, but would typically meet the definition of a Consumer (see 6.1) or Professional Informant (see 6.6). Referrers require at least a basic awareness of the signs and symptoms associated with ASD, along with an understanding of typical development, in order to identify that ASD may be a possible explanation of behavioural presentation. Where Referrers are health or educational professionals, these individuals are responsible for reviewing the presence of ASD symptoms, determining that an ASD Assessment is warranted and completing a Referral Form.

Referrers who administer standardised assessments must have current knowledge of, and experience in, administering the instrument. All qualifications and prerequisites for using the instrument in practice must be met.

CBR-2

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]

## 6.3 Coordinator

The Coordinator is a central contact who takes primary responsibility for communicating with the Consumer about the ASD assessment process, including the interface between the Diagnostic Evaluation and Functional and Support Needs Assessment. This coordination takes place from the time of referral until after the findings of the ASD assessment have been shared with the Consumer in a meeting and a written report. Specific tasks include:

- Explaining the ASD assessment process;
- Ensuring all documents are completed and shared in a timely fashion; and
- Being a key contact for the Consumer to ask questions (though, it is recognised that the Coordinator may then seek answers from other members of the multidisciplinary assessment team).

### 6.3.1 Professional Discipline

The Coordinator may be one of the Diagnosticians or Functional and Support Needs Assessors, or alternatively may be someone employed to support the team. The Diagnostician who receives the initial referral is responsible for taking on or delegating this role. Coordinators may have one of the following professional backgrounds:

- Medical;
- Allied health; or
- Administration.

### 6.3.2 ASD Specific Expertise

Coordinators must have appropriate operational knowledge of and/or experience in:

- Diagnostic Evaluation process;
- Functional and Support Needs Assessment process;
- Scheduling appointments, with flexibility to accommodate Consumer needs;
- Collating relevant background information; and
- Communicating with autistic individuals and their caregivers using a variety of mediums.

Coordinators may obtain this knowledge through:

- Non-assessed training;
- Peer learning; and/or
- Work experience.

CBR-1

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

## 6.4 Diagnostician

Diagnosticians are responsible for undertaking Diagnostic Evaluations, collecting information from Professional Informants, inviting additional Diagnosticians to participate in Tier 2 Diagnostic Evaluations (see Section 9.3), making diagnostic decisions, and sharing evaluation findings with Consumers. It is critical that Diagnosticians are both qualified in a certain professional discipline, as well as having demonstrated knowledge and expertise in ASD (Figure 2).

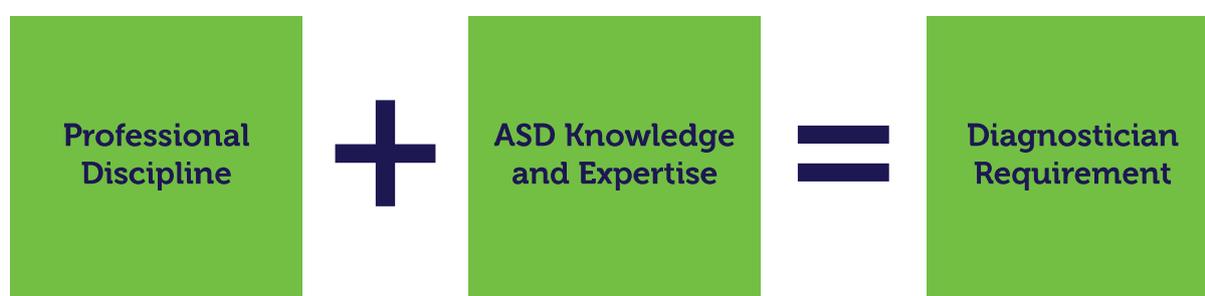


Figure 2. Requirements for an ASD Diagnostician

### 6.4.1 Professional Discipline

Diagnosticians must be qualified in one of the specific professional disciplines that provides a relevant foundational knowledge base for Diagnostic Evaluations for ASD. The professional disciplines that are recognised as suitable are listed below with specific membership requirements:

CBR-1

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]

CBR-2

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]

CBR-3

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]

CBR-1

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

CBR-2

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

CBR-3

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]

### 6.4.2 ASD Specific Expertise

In addition to belonging to an eligible professional discipline (with associated specialist skillsets, Table 3), Diagnosticians must also have current expert knowledge and experience in a wide range of areas that are relevant to all stages of a Diagnostic Evaluation for ASD.

CBR-1

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]

There are many ways that a Diagnostician can obtain and maintain expert knowledge and experience in these areas, and the pathway may vary with professional disciplines and individual career pathways. The recommended learning approach subsequently balances flexibility with rigorous standards.

CBR-1

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]

CBR-1

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

**Table 3. Training and key skills areas for Diagnosticians. Please note, Diagnosticians must not only have this base training, but also have acquired and demonstrated competency in the skills described in 6.4**

	<b>Paediatrician</b>	<b>Psychiatrist</b>	<b>Neurologist</b>	<b>Registered psychologist</b>	<b>Speech pathologist</b>	<b>Occupational therapist</b>
<b>Skills and expertise</b>	Medical doctors who have skills and expertise in the health and medical assessment and medical treatment of neonates (birth to four weeks) and children (up to 17 years).	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 17 years) and adult psychiatrists have expertise in adults (18 years and above).	Medical doctors who have skills and expertise in the assessment and treatment of individuals with conditions that effect the brain, spinal cord, nerve and muscle.	Allied health practitioners who have skills and expertise in the assessment and treatment of mental health and behavioural problems.	Allied health practitioners who have skills and expertise in the assessment and treatment of speech, language and communication disorders.	Allied health practitioners who have skills and expertise in the assessment and treatment of personal, activity and environmental factors to assist meaningful participation in activities, along with skills and expertise in sensory assessment.
<b>Training</b>	Successfully completed a medical degree accredited by the Australian Medical Council and at least one intern year. Successfully completed a further 3-year basic training in paediatrics and child health and 3-year advanced training program in one of the paediatrics divisions through the Royal Australian College of Physicians.	Successfully completed a medical degree accredited by the Australian Medical Council and at least one year of basic medical training in an accredited hospital. This is followed by successfully completing basic psychiatric training (3-year of stage 1 and 2), followed by two years of advanced training in adult or child and adolescent psychiatry (stage 3) in an accredited training network of the Royal Australian and New	Successfully completed a medical degree accredited by the Australian Medical Council and at least one 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.	Successfully completed a 4-year Australian Psychology Accreditation Council (APAC) endorsed university degree, followed by two 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)	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.	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.

		Zealand College of Psychiatrists.		typically involves at least an additional 2-3 years of formal training through either a masters or doctoral program, as well as one intern year following completion of post-graduate qualifications.		
<b>Membership</b>	<p>Registered as a Paediatrician with the Medical Board of Australia (part of the Australian Health Practitioner Regulation Agency).</p> <p>Fellow of the Royal Australasian College of Physicians - Paediatrics &amp; Child Health Division.</p>	<p>Registered as a Psychiatrists with the Medical Board of Australia (part of the Australian Health Practitioner Regulation Agency).</p> <p>Fellow of the Royal Australian and New Zealand College of Psychiatrists.</p>	<p>Registered as a Neurologist with the Medical Board of Australia (part of the Australian Health Practitioner Regulation Agency).</p> <p>Fellow of the Royal Australasian College of Physicians (with accreditation to practise as a Neurologist).</p>	<p>Registered as a Psychologist with the Psychology Board of Australia (part of the Australian Health Practitioner Regulation Agency).</p>	<p>Certified Practicing Member of Speech Pathology Australia.</p>	<p>Registered as an Occupational Therapist with the Occupational Therapy Board of Australia (part of the Australian Health Practitioner Regulation Agency).</p>

## 6.5 Functional and Support Needs Assessor

Functional and Support Needs Assessors are responsible for conducting Functional and Support Needs Assessments, collecting information from Professional Informants / Diagnosticians, identifying functional capacity, determining level of support needs, referring Consumers to supports, and sharing assessment findings with Consumers. Functional and Support Needs Assessors must both be qualified in a certain professional discipline, as well as having demonstrated knowledge and expertise in ASD (Figure 3).



*Figure 3. Requirements for a Functional and Support Needs Assessor*

### 6.5.1 Professional Discipline

Functional and Support Needs Assessors must be qualified in one of the specific professional disciplines that provides a relevant underlying knowledge base for Functional and Support Needs Assessments for ASD. The professional disciplines that are recognised as suitable are listed below with specific membership requirements:

CBR-1	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]
CBR-1	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]
CBR-3	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]

CBR-1

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

CBR-1

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]

CBR-1

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]

## 6.5.2 ASD Specific Expertise

In addition to belonging to an eligible professional discipline, Functional and Support Needs Assessors must also have current knowledge and experience in a wide range of areas that are relevant to all stages of a Functional and Support Needs Assessment for ASD.

CBR-1

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]

There are many ways that a Functional and Support Needs Assessor can obtain and maintain knowledge and experience in these areas.

#### CBR-1

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]

#### CBR-1

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]

## 6.6 Professional Informant

Professional Informants are responsible for providing clinical and aother information about the individual being assessed to support the Diagnostic Evaluation and Functional and Support Needs Assessment. The Professional Informant may have an existing working relationship with the individual being assessed, and/or meet with the individual for the purpose of contributing information to the ASD assessment.

### 6.6.1 Professional Discipline

Professional Informants must be a registered or equivalent member of a medical, allied health or education related professional discipline, and should hold a four year fulltime equivalent degree<sup>1</sup>. Suitable professional disciplines include (but are not limited to):

- Dietetic
- General practice
- Indigenous community health

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<sup>1</sup> Relevant professional experience may be assessed by the Diagnostician / Functional and Support Needs Assessor as equivalent to part or all of the four years of university study in exceptional circumstances, where a Professional Informant is not available who meets the qualification requirements and has adequate familiarity with the individual undergoing assessment.

- Nursing
- Occupational therapy
- Paediatrics
- Physiotherapy
- Preschool or early childhood educator
- Primary or secondary school teaching
- Psychiatry
- Psychology
- Social work
- Speech pathology.

### 6.6.2 ASD Specific Expertise

Professional Informants must have current knowledge of:

- Typical and atypical development in the domain in which they are providing information; and
- Typical and atypical development across the age range in which they are providing information;

Professional Informants may obtain and maintain this knowledge and experience through a combination of:

- University qualifications
- Other formally assessed training
- Non-assessed training
- Peer learning
- Work experience.

Professional Informants 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.

**CBR-2**

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]

# 7 ASD ASSESSMENT SETTINGS

## 7.1 Multiple Settings

Behaviours relevant to an ASD diagnosis are likely to vary according to different environmental contexts, and so it is important that information is collected about an individual's behaviour in a variety of settings during an ASD assessment. It is recognised that it is likely not feasible for all professionals undertaking an ASD assessment to conduct face-to-face visits in each relevant community setting (see 7.2.2). Flexibility is required to ensure that the individual's behaviours are assessed by suitable professionals in the most appropriate community settings, whilst achieving an adequate balance between obtaining sufficient quality information and avoiding excessive use of resources.

Information on an individual's behaviour in a range of settings can be obtained through a combination of:

- Observing behaviours in a face-to-face clinic or community visit;
- Observing behaviours in a video conferencing session;
- Observing behaviours in video recordings supplied by the Consumer(s) or Professional Informant(s).
- Collecting information from Consumers during an interview (conducted in either a clinic, community or telehealth setting) or survey; and/or
- Collecting information from Professional Informants within the individual's community through verbal or written communication.

CBR-1

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]

## 7.2 Types of Settings

### 7.2.1 Clinic Setting

A clinic setting refers to a medical or allied health practice that an individual being assessed for ASD visits specifically for assessment purposes. A clinic setting consists of all spaces within the practice, such as waiting, interview and/or clinical rooms. A clinic setting is considered an appropriate venue for an ASD assessment. However, it is not necessary to conduct part of the ASD Assessment in a clinic if there is an appropriate space to undertake assessment in a community setting that is relevant to the individual. The advantages of a clinic setting include the ability to:

- Standardise the physical, sensory and social environment;
- Observe the individual in new environments, where they may be unable to rely on their usual strategies or supports;
- Avoid peers becoming aware of the ASD assessment process;
- Offer a convenient “one stop” location where all aspects of the ASD assessment can be conducted consecutively; and/or
- Potentially minimise costs and wait times for the ASD assessment by co-locating Diagnosticians and Professional Informants.

CBR-1

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]

### 7.2.2 Community Setting

A community setting refers to one of the familiar environments where the individual being assessed for ASD undertakes one or more of their usual activities. Examples of a community setting included (but are not restricted to) the individual’s home, childcare centre, playground, friend or family member’s home, leisure facility, social situation, school, tertiary institution or workplace. An advantage of undertaking aspects of an ASD assessment in a community setting include the opportunity to:

- Observe the individual (and family) within a familiar environment where anxiety levels may be minimised;
- Observe typical behaviours within their usual context, where the interaction between the individual, environment and activity demands can be evaluated; and/or
- Minimise travel burden on the individual (and family).

CBR-1

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

### 7.2.3 Telehealth Setting

A telehealth setting refers to interactions using telephone conversations, video conferencing and/or reviewing video recordings. In exceptional circumstance, information for the ASD assessment can be collected in a telehealth setting only (without meeting face-to-face with the Consumer in a clinic or community setting), where conducting a face-to-face assessment in a clinic or community setting is very difficult. This is restricted to situations where the Consumer lives in a regional or remote location without access to ASD assessment services,

or other substantial travel restrictions that prevent a face-to-face assessment occurring (such as challenges relating to sensory or anxiety symptoms).

**CBR-1**

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]

**CBR-2**

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]

# 8 INITIATING AN ASD ASSESSMENT

## 8.1 Recognition of Signs and Symptoms of ASD

Recognition of the signs and symptoms of possible ASD and prompt referral for an ASD assessment are key factors in an individual receiving a timely diagnosis of ASD (Tables 10 – 12).

### 8.1.1 Consumer and Community Observations

For young children, parents / caregivers are most likely to be the first to recognise developmental differences, though these may also be raised by primary health clinicians (e.g., maternal and/or child health nurses and general practitioners) or by childcare educators. For school-aged children, parents / caregivers, primary health clinicians and school teachers are the most likely individuals to bring developmental and behavioural symptoms to attention. Adults may identify these matters themselves or be prompted by a partner, family member, friend or health professional (e.g., counsellor).

It is critical for professionals to recognise that parents know their own children very well, and that the developmental concerns of the parent or caregiver must be taken seriously, even if these are not shared by others. There is evidence that parents have moderate-to-high levels of accuracy in identifying clinically-relevant developmental matters in their children [14-16]. If older children or adults have queries about themselves, then these must also be taken seriously.

### 8.1.2 Evidence of Signs and Symptoms

An investigation of the signs and symptoms of ASD must be appraised within the context of an individual's overall development, and so the administration of standardised developmental screening measures (Table 4) are strongly encouraged (when age appropriate). If the findings from a developmental screening measure (or developmental history in the case of older individuals) suggests the need for further clinical investigation, then information can be obtained about ASD signs and symptoms using a screening tool that specifically targets ASD behaviours. Although ASD screening tools may be useful in gathering information about ASD signs and symptoms in a structured way, there is currently little published evidence to suggest that any one tool can be used in isolation to determine whether an individual should be referred for an ASD assessment [17].

**Table 4. Developmental screening tools used commonly in Australia to identify potential developmental delays that warrant further investigation**

Instrument	Domains	Age range	Completion time	Guides follow-up	Sensitivity / Specificity *
<b>Instruments completed by parents or caregivers</b>					
<b>Ages and Stages Questionnaire – 3<sup>rd</sup> edition [18]</b>	<ul style="list-style-type: none"> <li>• Communication</li> <li>• Gross motor</li> <li>• Fine motor</li> <li>• Problem solving</li> <li>• Personal-social</li> </ul>	Birth to 66 months	~ 10 – 15 minutes	Yes	Moderate / Moderate
<b>Parents' Evaluations of Developmental Status [19]</b>	<ul style="list-style-type: none"> <li>• Global/cognitive</li> <li>• Expressive language and articulation</li> <li>• Receptive language</li> <li>• Fine motor</li> <li>• Gross motor</li> <li>• Behaviour</li> <li>• Social-emotional</li> <li>• Self-help</li> <li>• School</li> </ul>	Birth to 7 years, 11 months	~ 10 minutes	Yes	Moderate / Moderate
<b>Child Development Inventories [20]</b>	<ul style="list-style-type: none"> <li>• Gross motor</li> <li>• Fine motor</li> <li>• Language</li> <li>• Comprehension</li> <li>• Personal-social</li> </ul>	Three to 72 months	~ 10 minutes	Yes	Moderate / Moderate
<b>Instruments completed by professionals</b>					
<b>The Brigance Early Childhood Screens III [21]</b>	<ul style="list-style-type: none"> <li>• Expressive language</li> <li>• Receptive language</li> <li>• Gross motor</li> <li>• Fine motor</li> </ul>	Birth to end of first grade	~ 10 – 15 minutes	Yes	Moderate - high / High

	<ul style="list-style-type: none"> <li>• Academics/pre-academics</li> <li>• Self-help</li> <li>• Social-emotional skills</li> </ul>				
<b>Battelle Developmental Inventory – Second edition (Screening test) [22]</b>	<ul style="list-style-type: none"> <li>• Personal-social</li> <li>• Adaptive</li> <li>• Motor</li> <li>• Communication</li> <li>• Cognitive</li> </ul>	Birth to 7 years, 11 months	~ 10 – 30 minutes	Yes	Moderate / Moderate
<b>Denver Developmental Screening Test, 2<sup>nd</sup> edition [23]</b>	<ul style="list-style-type: none"> <li>• Expressive language</li> <li>• Receptive language</li> <li>• Gross motor</li> <li>• Fine motor</li> <li>• Academics / pre-academics</li> <li>• Self-help</li> <li>• Social-emotional skills</li> </ul>	Birth to 6 years	~ 10 – 20 minutes	Yes	Moderate / Low
<p><i>*Sensitivity indicates how well a measure correctly identifies children with delay/disability. Specificity indicates the degree to which a measure correctly identifies children without delay/disability</i></p>					

The decision to refer an individual for further assessment cannot be simplified to an algorithm with a clear-cut behavioural threshold, and requires judgment based upon a range of factors. Table 5 outlines some of these key factors, and the evidence that these factors provide to indicate that a referral is appropriate [2]:

<b>Factor</b>	<b>Increased weight for a referral</b>
<b>Severity of signs/symptoms associated with ASD</b>	More severe sign/symptoms
<b>Duration of signs/symptoms associated with ASD</b>	Longer duration of signs/symptoms
<b>History of developmental regression</b>	A history of a loss of language or social skills

<b>Impact of signs/symptoms on individual and/or family functioning</b>	Significantly interferes with the daily functioning of the individual and/or family
<b>Level of individual and/or caregiver concern of the signs/symptoms</b>	Moderate to substantial concern
<b>Settings in which signs/symptoms associated with ASD are present</b>	Present in a range of settings
<b>Testing of hearing</b>	Hearing impairments have been ruled out, however communication impairments are present
<b>Presence of other factors known to be associated with ASD</b>	<p>Presence of any of the following well-established risk factors [24-26]:</p> <ul style="list-style-type: none"> <li>• Advanced maternal age at conception, usually defined as being over 40 years of age;</li> <li>• Advanced paternal age at conception, usually defined as being over 40 years of age;</li> <li>• Birth complications associated with ischemia or hypoxia;</li> <li>• Preterm birth (less than 37 weeks);</li> <li>• Low birthweight (&lt;2500g).</li> </ul>
<b>Probability of alternative explanations for the signs/symptoms</b>	No obvious alternative explanations

Table 5 is to be used as a guide to weigh a variety of evidence, and is not to be used as a definitive referral algorithm. Not every individual presenting with these risk factors will receive a diagnosis of ASD, and not every autistic individual will present with these risk factors.

**CBR-1**

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].

## 8.2 Making a Referral for an ASD Assessment

If a professional has been determined that an individual has sufficient signs and symptoms to prompt a referral for an ASD assessment, this individual (the 'Referrer') should explain the rationale for an ASD assessment and ask if the Consumer would like to proceed with a referral. In addition, the Referrer should link the Consumer to support services to address any urgent needs identified during the screening process, at the same time as referring for

an ASD assessment. A Consumer is able to self-refer for an ASD assessment, and may proceed directly with a referral through their General Practitioner. A referral for an ASD assessment is activated through completing a Referral Form (Web Resources) addressed to the Tier 1 Diagnostician that includes the following information:

- Name of Diagnostician to receive referral;
- Referrer name, contact details and relationship with individual;
- Basic demographic information of the individual being referred for assessment, including name, age, gender, caregiver (if appropriate) and contact details;
- Reason for referral;
- Description of ASD signs and symptoms that have been reported by the Consumer or other people who know the individual well;
- Description of ASD signs and symptoms that have been observed by the Referrer, including the results of any standardised developmental or ASD screening tools administered;
- Details of any barriers the Consumer may have in attending an appointment at a clinic;
- List of existing reports provided and/or available from the Consumer; and
- Details of any support services that have been established to address urgent support needs identified during the screening process.

CBR-2

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]

### 8.3 Acting on a Referral for an ASD Assessment

If the Tier 1 Diagnostician is not the Coordinator for the ASD assessment, there should be internal systems to ensure that the Coordinator receives the referral. Prior to acting on a referral, the Coordinator of the ASD assessment plays a key role in ensuring the Referral Form:

- Provides a clear rationale that an ASD assessment is appropriate; and
- Contains all necessary information outlined in Section 8.2, including the Consumer's contact details.

The Coordinator provides the main point of contact between the multidisciplinary assessment team and the Consumer throughout the ASD assessment. Once the Referral Form is checked for completeness, the Coordinator will make contact with the Consumer to:

- Explain the ASD Assessment process from start (receipt of referral) to finish (communication of ASD assessment findings);

- Provide written information about the ASD Assessment process for the Consumer to keep and consider in their own time;
- Explain that the Coordinator is the key contact person to ask questions during the ASD Assessment process;
- Provide the Coordinator's contact details;
- Provide an opportunity to ask questions about the ASD Assessment process;
- Facilitate the Consumer completing any intake, consent and/or self-report forms requested by the Diagnostician or Functional and/or Support Needs Assessor;
- Collect copies of existing reports from the Consumer (or from existing medical, health and/or education professionals with consent from the Consumer);
- Schedule the first appointments with the Diagnostician and Functional and Support Needs Assessor;
- Remind the Consumer of appointment details and instructions to maximise attendance rates and information availability.

The Coordinator will continue to support the Consumer in a similar way for the duration of the ASD assessment process.

CBR-1

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]

# 9 DIAGNOSTIC EVALUATION

## 9.1 Purpose

The purpose of a Diagnostic Evaluation is to determine whether an individual meets diagnostic criteria for ASD.

## 9.2 Diagnostic Criteria

Two sets of diagnostic criteria for ASD are recognised in Australia. The most commonly used set of criteria in Australia is the Diagnostic and Statistical Manual of Mental Disorders (DSM), for which the current version is the DSM-5 (Table 6, [27]). The International Statistical Classification of Diseases and Related Health Problems is also used, with the current version being the ICD-10 (Table 6, [28]). The next version of the ICD (ICD-11) is due to be published in 2018, and the beta version indicates that the diagnostic criteria for ASD will be aligned with the DSM-5 and introduce a strong focus on assessing functional impairment (Table 6, [29]).

CBR-1

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]

**Table 6. Diagnostic criteria for ASD**

DSM-5 [27]	ICD-10 [28]	ICD-11 Beta Draft [29]
1. Persistent deficits in social communication and social interaction across multiple contexts (currently or by history): <ul style="list-style-type: none"> <li>• Social-emotional reciprocity;</li> <li>• Nonverbal communicative behaviours; and</li> <li>• Developing, maintaining, and</li> </ul>	1. Abnormal functioning in reciprocal social interaction.  2. Abnormal functioning in communication.	1. Persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication

understanding relationships.		
<p>2. Restricted, repetitive patterns of behaviour, interests, or activities in at least two (currently or by history):</p> <ul style="list-style-type: none"> <li>• Stereotyped or repetitive motor movements, use of objects, or speech</li> <li>• Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour</li> <li>• Highly restricted, fixated interests that are abnormal in intensity or focus</li> <li>• Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment</li> </ul>	<p>3. Abnormal functioning in restricted, stereotyped, repetitive behaviour.</p>	<p>2. Restricted, repetitive, and inflexible patterns of behaviour and interests</p>
<p>3. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)</p>	<p>3. Presence of abnormal or impaired development that is manifest before the age of three years</p>	<p>3. Onset during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities</p>
<p>4. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning</p>		<p>4. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context.</p>
<p>5. Not better explained by another diagnosis</p>		

## 9.3 Diagnostic Evaluation Structure

To ensure that the Diagnostic Evaluation is both accurate and efficient for the full range of ASD presentations, the guideline incorporates a degree of flexibility that enables the process to be tailored to the complexity of the individual's clinical presentation. The guideline recommends two sequential 'tiers' for Diagnostic Evaluation (see Figure 4). All individuals undergo a Tier 1 Diagnostic Evaluation, which involves a simplified assessment process to determine if an ASD diagnosis can be confirmed or ruled-out with certainty. Where an ASD diagnosis cannot be confirmed or ruled-out with certainty at Tier 1, an individual continues to a Tier 2 Diagnostic Evaluation. A Tier 2 Diagnostic Evaluation incorporates additional members of a multidisciplinary assessment team and a more in-depth assessment of the specific areas where there was diagnostic uncertainty.

CBR-2

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]

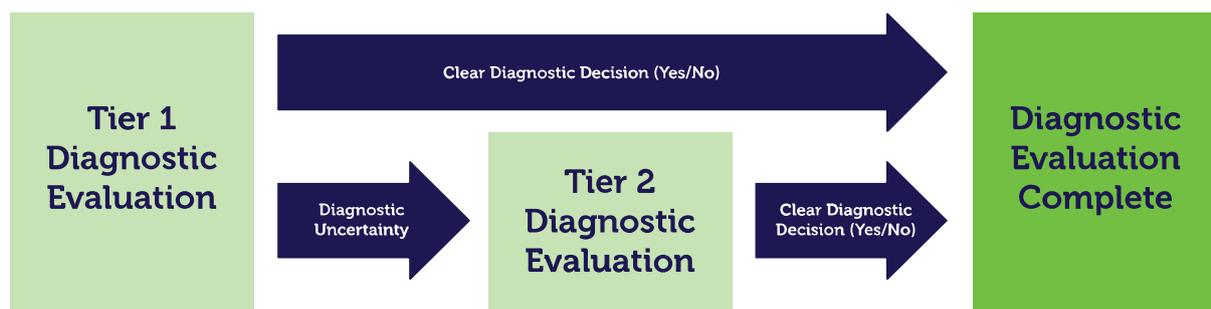


Figure 4. Relationship between two tiers of a Diagnostic Evaluation.

## 9.4 Tier 1 Diagnostic Evaluation

A Tier 1 Diagnostic Evaluation recognises that there are a proportion of individuals whose presentation is sufficiently clear that a diagnostic decision can be reliably made with certainty by a limited number of experienced members of a multidisciplinary assessment team, drawing on information collected with or without visiting multiple settings or administering standardised assessments.

### 9.4.1 Professional Involvement

CBR-2

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]

## 9.4.2 Settings

CBR-1

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]

CBR-1

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]

## 9.4.3 Information Collection

To obtain a comprehensive understanding of the individual being assessed, a Tier 1 Diagnostic Evaluation must involve the collection of information on all of (but not limited to) the following topics:

- **Medical and health history:** Information from the antenatal, perinatal, neonatal, past and current periods in relation to hearing, visual, physical, intellectual and mental health conditions;
- **Family history:** Presence of medical, psychiatric, and neurodevelopmental disorders (including ASD) among nuclear or extended family members, as well as relevant social and environment factors (e.g. family violence, substance abuse, neglect);
- **Developmental history:** How the individual has presented during their lifetime in terms of developmental milestones for communication, social, gross / fine motor and personal care skills, as well as the presence of any developmental regression;
- **ASD specific symptoms:** Behaviours relating to social communication/interaction and restricted, repetitive patterns of behaviour outlined in either the current DSM or ICD diagnostic criteria; and
- **Other relevant behaviours and/or symptoms:** Screening to determine if further investigations are required to explore if differential diagnosis should be considered or a co-occurring condition is present.

CBR-1

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]

Information collected from a variety of evidence sources can greatly assist the development of a comprehensive clinical picture of an individual. These include:

- **File review** of existing assessment reports, early intervention / medical records, parent records of early development (e.g. baby books, home video footage), school records and evidence of any childhood traumatic experiences;
- **Interview with the individual** being assessed for ASD (if appropriate based on age and communication abilities), where information is obtained by asking semi-structured open ended questions and may be supplemented by standardised questionnaires completed before the interview;
- **Interview with a caregiver** (if appropriate based on age and communication abilities, or with consent) or a support person who knows the individual well (e.g. parent, sibling, partner, friend, teacher), where information is obtained by asking semi-structured open ended questions and may be supplemented by standardised questionnaires completed before the interview;
- **Observation of the individual** being assessed for ASD, where the Diagnostician purposefully interacts with the individual in a manner that is likely to elicit behaviours consistent with ASD. A standardised observational tool may be used for this purpose, but is not required at Tier 1; and
- **Medical evaluation of the individual** being assessed for ASD, consisting of neurological and physical history and examination to assess whether there are medical causes and/or associations with the behavioural presentation of the individual (specific topics covered in the Web Resources template).

Where the Tier 1 Diagnostician is not a medical professional, they must arrange for a medical professional to complete the medical evaluation. Paediatricians, child psychiatrists or paediatric neurologists (for children), or adult psychiatrists or adult neurologists (for adults), who meet the requirements for a Diagnostician could complete a medical evaluation in the role of a Tier 2 Diagnostician (if the assessment progresses to Tier 2). Alternatively, a medical professional from one of these disciplines or a general practitioner could complete a medical evaluation in the role of Professional Informant. A template example of a Medical Evaluation Form is provided as a Web Resource for Professional Informants to use in this circumstance.

- **Discussion with the Professional Informant(s)** to obtain further information on the individual's signs, symptoms and/or behaviours in other settings.

#### CBR-1

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]

#### 9.4.4 Diagnostic Decision Making

Once sufficient information has been collected, a Diagnostician undertakes a diagnostic decision making process and evaluates the next step in the clinical pathway. Diagnostic algorithms for DSM-5 ([27], Figure 5) and ICD-10 ([28], Figure 6) have been provided.

CBR-1

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]

A Tier 1 Diagnostic Evaluation will result in one of the following three outcomes:

1. Diagnostic certainty that the individual does meet criteria for ASD;
2. Diagnostic certainty that the individual does not meet criteria for ASD; or
3. Diagnostic certainty has not yet been achieved in relation to whether the individual meets criteria for ASD or not, and a Tier 2 Diagnostic Evaluation is required.

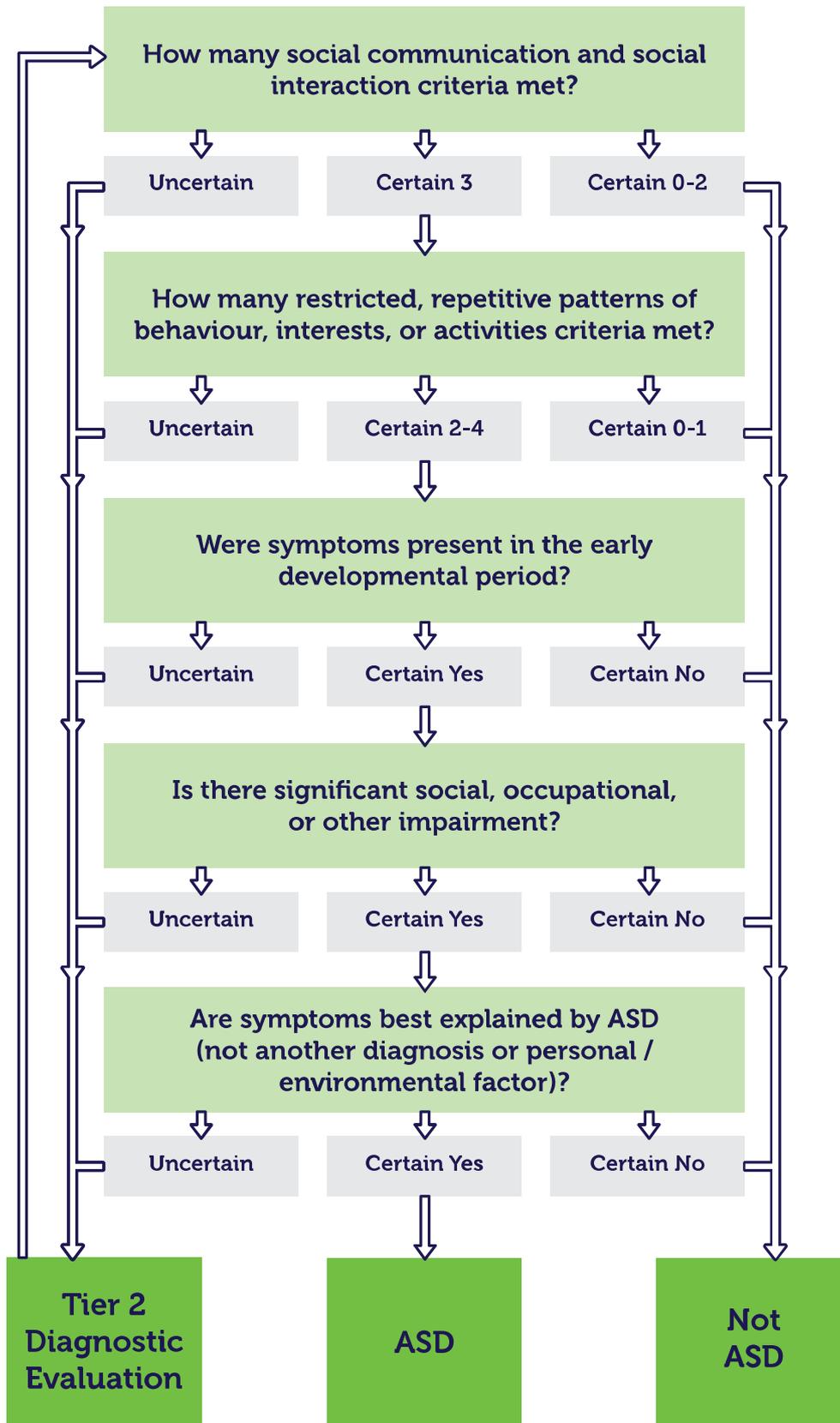


Figure 5. Diagnostic algorithm for DSM-5

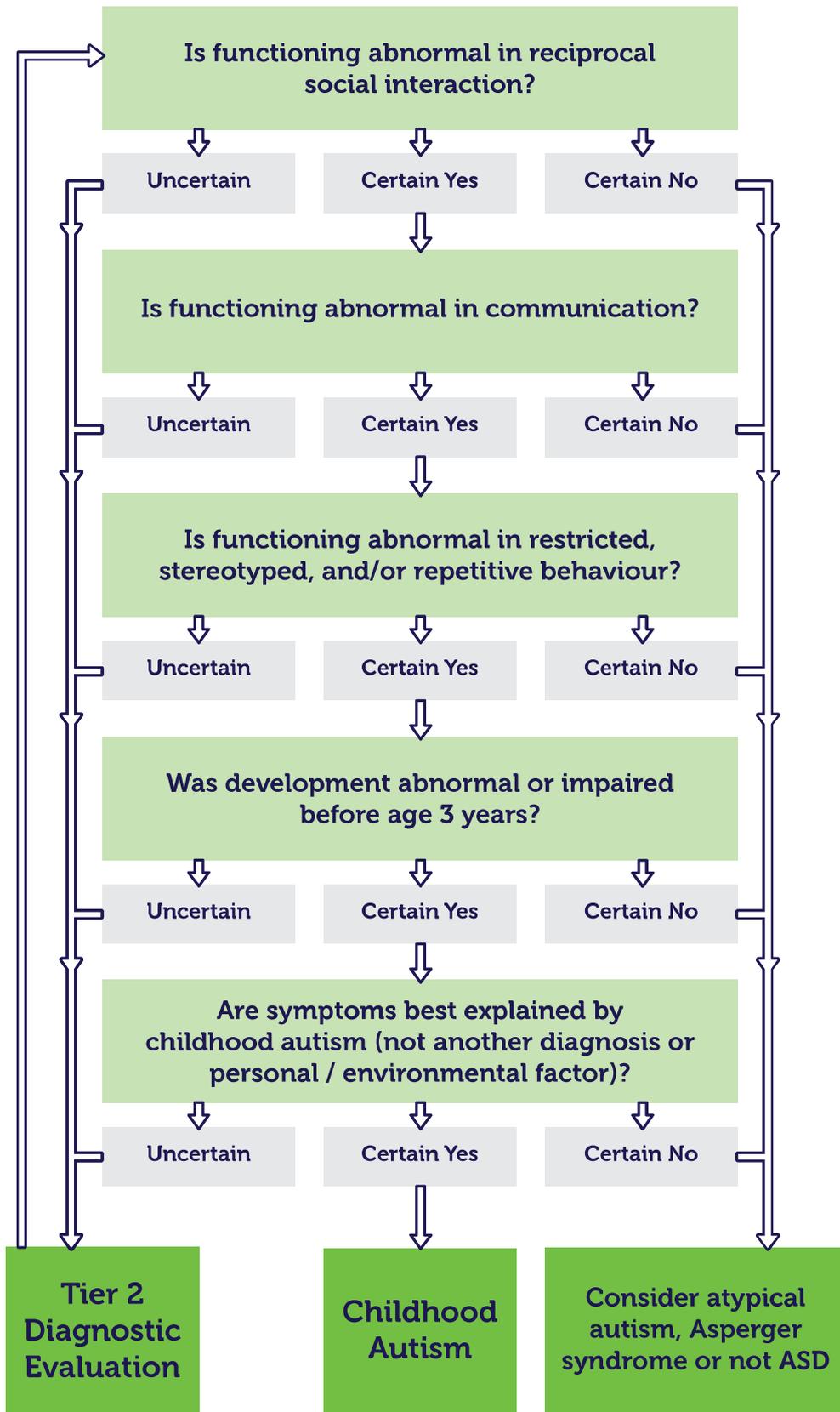


Figure 6. Diagnostic algorithm for ICD-10

## 9.5 Tier 2 Diagnostic Evaluation

A Tier 2 Diagnostic Evaluation recognises that there are individuals whose presentation is more complex or subtle, and that an accurate diagnostic determination of these individuals requires a broader multidisciplinary assessment team, who draw on information collected from multiple settings and through administering standardised assessments, to accurately make a diagnostic decision with certainty.

### 9.5.1 Professional Involvement

A Tier 2 Diagnostic Evaluation is conducted by at least two Diagnosticians, with input from at least two Professional Informants. (Tier 1 Diagnosticians and Professional Informants are included in this team). The additional Diagnostician(s) and Professional Informant(s) should be selected on the basis of areas in which there was diagnostic uncertainty during the Tier 1 Diagnostic Evaluation. All members of the multidisciplinary assessment team should come from different professional disciplines or specialties.

CBR-2

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]

Where a Tier 2 Diagnostic Evaluation is required, the Tier 1 Diagnostician should refer the individual to a second Diagnostician and/or Professional Informant who has the necessary professional discipline and ASD specific expertise to address the areas of diagnostic uncertainty. Table 7 provides guidance on the professional disciplines with specialist skills in a variety of co-occurring concerns observed during ASD assessments.

### 9.5.2 Settings

CBR-1

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]

When it is not feasible for one of the Diagnosticians to conduct a face-to-face visit in a community setting (e.g. regional and remote locations), a direct observation can be made via video conference or by reviewing a recording of the individual in a community setting. In this circumstance, the Diagnostician must seek input from a Functional and Support Needs Assessor and/or Professional Informant who has met with the individual face-to-face.

CBR-1

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]

**Table 7. Professional discipline specialists for co-occurring concerns observed during ASD assessments**

Co-occurring Concerns	Diagnostician / Functional and Support Needs Assessor	Example of Additional Professional Informant
<b>Physical and Sensory</b>		
<b>Epilepsy, seizures or neurodevelopmental concerns reported</b>	<ul style="list-style-type: none"> <li>• Neurologist</li> <li>• Paediatrician</li> <li>• Psychiatrist</li> </ul>	<ul style="list-style-type: none"> <li>• General practitioner</li> </ul>
<b>Gastrointestinal difficulties, such as constipation, diarrhoea, abdominal bloating, discomfort, irritability, gastroesophageal reflux and/or vomiting</b>	<ul style="list-style-type: none"> <li>• Paediatrician</li> </ul>	<ul style="list-style-type: none"> <li>• Dietitian</li> <li>• General practitioner</li> </ul>
<b>Genetic syndrome(s) concerns, based on family history of and/or congenital physical anomalies</b>	<ul style="list-style-type: none"> <li>• Paediatrician</li> <li>• Psychiatrist</li> </ul>	<ul style="list-style-type: none"> <li>• Geneticist</li> </ul>
<b>Global developmental functioning concerns</b>	<ul style="list-style-type: none"> <li>• Paediatrician</li> <li>• Psychiatrist (child)</li> <li>• Registered psychologist</li> </ul>	<ul style="list-style-type: none"> <li>• Occupational therapist</li> <li>• Speech pathologist</li> </ul>
<b>Hearing difficulties</b>	<ul style="list-style-type: none"> <li>• Speech pathologist</li> </ul>	<ul style="list-style-type: none"> <li>• Audiologist</li> </ul>
<b>Motor and movement issues, such as gross or fine motor development delays</b>	<ul style="list-style-type: none"> <li>• Occupational therapist</li> <li>• Paediatrician</li> </ul>	<ul style="list-style-type: none"> <li>• Physiotherapist</li> </ul>
<b>Oral health issues</b>		<ul style="list-style-type: none"> <li>• Dentist</li> </ul>
<b>Sensory processing differences, such as hypersensitivity or hyposensitivity</b>	<ul style="list-style-type: none"> <li>• Occupational therapist</li> <li>• Registered psychologist (clinical or educational and developmental)</li> </ul>	
<b>Vision difficulties</b>		<ul style="list-style-type: none"> <li>• Ophthalmologist</li> <li>• Optometrist</li> </ul>
<b>Other medical or sensory issues not described above</b>	<ul style="list-style-type: none"> <li>• Paediatrician</li> </ul>	<ul style="list-style-type: none"> <li>• Medical specialists</li> </ul>

	<ul style="list-style-type: none"> <li>• Psychiatrist</li> </ul>	
<b>Mental and Social</b>		
<b>Cognitive and intellectual functioning indicating atypical development</b>	<ul style="list-style-type: none"> <li>• Paediatrician</li> <li>• Psychiatrist</li> <li>• Registered psychologist (clinical or educational and developmental)</li> </ul>	<ul style="list-style-type: none"> <li>• Occupational therapist</li> <li>• Speech pathologist</li> </ul>
<b>Behavioural concerns that may include -compulsive behaviours, tic disorders, selective mutism, excessive challenging behaviour and/or tantrums</b>	<ul style="list-style-type: none"> <li>• Paediatrician</li> <li>• Psychiatrist</li> <li>• Registered psychologist</li> </ul>	
<b>Mental health or psychiatric concerns (including caregiver mental health). This may include mood or anxiety concerns, self-harm, suicidal ideation and/or psychosis</b>	<ul style="list-style-type: none"> <li>• Paediatrician</li> <li>• Psychiatrist</li> <li>• Registered psychologist</li> </ul>	<ul style="list-style-type: none"> <li>• Occupational therapist</li> </ul>
<b>Attention difficulties and/or hyperactivity</b>	<ul style="list-style-type: none"> <li>• Paediatrician</li> <li>• Psychiatrist</li> <li>• Registered psychologist</li> </ul>	
<b>Social relationships, including bullying, social isolation, social and/or romantic relationship difficulties</b>	<ul style="list-style-type: none"> <li>• Psychiatrist</li> <li>• Registered psychologist</li> <li>• Speech pathologist</li> </ul>	<ul style="list-style-type: none"> <li>• Social worker</li> <li>• Psychologist</li> <li>• Occupational therapist</li> <li>• Speech pathologist</li> </ul>
<b>Trauma or deprivation</b>	<ul style="list-style-type: none"> <li>• Psychiatrist</li> <li>• Registered psychologist (clinical specialty)</li> </ul>	<ul style="list-style-type: none"> <li>• Social worker</li> <li>• Psychologist</li> </ul>
<b>Functional</b>		
<b>Communication and language difficulties, such as potential speech or language delay / disorder and stuttering</b>	<ul style="list-style-type: none"> <li>• Speech pathologist</li> </ul>	

<b>Feeding issues, such as food selectivity, diet concerns or meal time challenges</b>	<ul style="list-style-type: none"> <li>• Occupational therapist</li> <li>• Paediatrician</li> <li>• Speech pathologist</li> </ul>	<ul style="list-style-type: none"> <li>• Dietitian</li> </ul>
<b>Literacy issues, such as reading and writing difficulties</b>	<ul style="list-style-type: none"> <li>• Speech pathologist</li> <li>• Registered psychologist (clinical or educational and developmental specialty)</li> </ul>	
<b>General function or adaptive behaviour difficulties in one or more activity area that enables an individual to fully participate in life (e.g., self-care, play, school, employment or community safety).</b>	<ul style="list-style-type: none"> <li>• Occupational therapist</li> <li>• Registered psychologist (clinical specialty)</li> </ul>	<ul style="list-style-type: none"> <li>• Speech pathologist</li> </ul>
<b>Sleep difficulties, including initiation, maintenance or disordered breathing during sleep</b>	<ul style="list-style-type: none"> <li>• Paediatrician</li> <li>• Psychiatrist</li> <li>• Psychiatrist</li> <li>• Registered psychologist (clinical specialty)</li> </ul>	<ul style="list-style-type: none"> <li>• General practitioner</li> <li>• Sleep and respiratory physician</li> </ul>

### 9.5.3 Information Collection - Standardised ASD Diagnostic Tool

In addition to information collected during Tier 1 (see 9.4.3), a Tier 2 Diagnostic Evaluation should involve the administration of at least one standardised ASD diagnostic tool, that is appropriate for the age, communication ability and gender of the individual undergoing assessment. These instruments provide the benefit of a structured and consistent way for collecting information about the presence and extent of behaviours frequently associated with ASD. It is recommended that composite and sub-scale scores are only used to inform an ASD diagnosis if the instrument has acceptable psychometric properties and diagnostic accuracy in relation to the diagnostic criteria selected. The Diagnostician should explain the purpose of the standardised ASD diagnostic tool to the Consumer.

Adequate diagnostic accuracy is defined as having both sensitivity and specificity scores, or a correct classification rating, of 80% or above for similar populations across multiple published research studies [2, 30, 31]. The only standardised ASD diagnostic tool that is consistently recommended by systematic reviews of research literature as meeting this criteria is the Autism Diagnostic Observation Schedule (ADOS), which is based on DSM-IV criteria [1, 2, 31-33]. The most recent version (ADOS-2) is based on DSM-5 criteria, though widespread published evidence for the psychometric properties of this version are not yet established [34, 35]. However, the community consultation findings suggest that the ADOS-2 is well supported in Australian practice.

There is emerging and/or inconsistent evidence that the following instruments may have adequate diagnostic accuracy for ASD (among specific populations):

- Autism Diagnostic Interview-Revised (ADI-R) [community consultation and 1, 31, 32]
- ADI / ADI-R in combination with the ADOS [community consultation and 2, 31]
- Autism Mental Status Exam (AMSE) [36, 37]
- Autism Spectrum Diagnostic Interview (ASDI) [1]
- Autism Spectrum Disorders - Diagnostic for Children (ASD-DC) [31]
- Checklist for Autism Spectrum Disorder (CASD) [31, 38]
- Childhood Autism Rating Scale, original and second edition (CARS / CARS2) [31, 32, 39]
- Developmental, Dimensional and Diagnostic Interview (3Di) [2, 31, 32]
- Naturalistic Observation Diagnostic Assessment (NODA) [40]
- Ritvo Autism Asperger Diagnostic Scale, original and revised versions (RAADS / RAADS-R) [1, 31]

CBR-1

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]

#### 9.5.4 Information Collection - Specialist Assessments

During a Tier 2 Diagnostic Evaluation, information should be collected through an individually-tailored selection of specialist assessments, including standardised instruments and non-standardised data collection tools, to further investigate aspects where diagnostic certainty is lacking for the individual undergoing assessment. These additional assessments may be administered by one of the Diagnosticians, the Functional and Support Needs Assessor or a Professional Informant. The Diagnostician should explain the relevance of the standardised specialist assessments to the Consumer.

Examples of possible assessments that may be selected for a Tier 2 Diagnostic Evaluation are described in Table 8.

CBR-1

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]

**Table 8. Possible specialist assessment choice for a Tier 2 Diagnostic Evaluation to address areas of uncertainty in relation to the diagnostic decision**

Domain being assessed	Type of specialist assessment
Social interaction and/or communication domain(s)	Communication assessment (e.g. speech, language, social communication and social interaction)
Repetitive patterns of behaviour, interests, or activities domain	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)
Possible differential or co-occurring diagnosis	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 screening or diagnostic tool to identify the presence of a range of mental health 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)	

### 9.5.5 Diagnostic Decision Making

At Tier 2, the diagnostic decision (Figures 5 and 6) is made by Diagnosticians discussing the assessment findings through a variety of communications including, correspondence and/or face-to-face, telephone or videoconference meetings.

#### CBR-1

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]

## CBR-2

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]

A Tier 2 Diagnostic Evaluation will result in one of the following three outcomes:

1. Diagnostic certainty that the individual does meet criteria ASD;
2. Diagnostic certainty that the individual does not meet criteria ASD;
3. Consensus on a diagnostic decision was not achieved among the Diagnosticians following an extensive Tier 2 Diagnostic Evaluation, and the diagnostic decision should be deferred until re-assessment after a specified period of time.

If the diagnostic decision is deferred until re-assessment, the following steps should be followed:

- All information collected during the Tier 1 and Tier 2 Diagnostic Evaluations, along with the Functional and Support Needs Assessment, should be made available to the Diagnosticians conducting the re-assessment (where possible);
- The Diagnostic Evaluation report should specify aspects where diagnostic certainty was achieved and not achieved; and
- Re-assessment should focus on clarifying aspects where diagnostic uncertainty was present during the initial Diagnostic Evaluation, and unnecessary duplication of previously collected data should be avoided (although it is recognised that some topics may be revisited to determine if signs, symptoms or behaviours have changed).

# 10 FUNCTIONAL AND SUPPORT NEEDS ASSESSMENT

## 10.1 Purpose

The purpose of a Functional and Support Needs Assessment is to obtain information that can be used to guide future provision of supports and resources to assist the individual (and their caregivers, if appropriate) to reach their full potential in relation to activities and participation in society.

## 10.2 Functional and Support Needs Assessment Structure

The Functional and Support Needs Assessment is a parallel assessment process that can be undertaken at any time throughout the Diagnostic Evaluation. The aim is to assess a broad range of functional domains that are relevant to the individual, in order to identify support needs, establish goals and link to the most appropriate support services.

It is recommended that the Functional and Support Needs Assessment process is dynamic and allows Consumers to be linked to appropriate supports as soon as possible after support needs are identified.

The Functional and Support Needs Assessment (Figure 7) is described in relation to the two phases of Functional Assessment (current status) and Support Needs Assessment (current and future requirements).



**Figure 7. Relationship between two components of a Functional and Support Needs Assessment.**

**CBR-1**

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]

## 10.3 Functional Assessment

### 10.3.1 Professional Involvement

CBR-2

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]

A Functional and Support Needs Assessor may be:

- A Diagnostician or Professional Informant who was involved in the Diagnostic Evaluation; or
- An individual who meets requirements to be either a Diagnostician or Professional Informant, but who was not involved in the Diagnostic Evaluation.

### 10.3.2 Settings

The Functional Assessment should take place in a setting in which the Consumer feels comfortable and confident to discuss their functional status. This may be in a clinic or community setting. Information must be collected about the individual's function in relation to all relevant community settings, although it is not essential for the assessor to visit these locations.

CBR-2

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]

### 10.3.3 Information Collection

Information collected from a variety of evidence sources can greatly assist the development of a comprehensive picture of the functional abilities of an individual. These include:

- File review of existing assessment reports;
- Interview with the Consumer;
- Observation of the individual;
- Communication with Professional Informant(s); and/or
- Standardised assessments.

## CBR-1

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

A standardised functional tool (otherwise known as an adaptive behaviour assessment) would provide:

- Descriptive information about the individual's functional strengths and challenges;
- Total score to describe the individual's overall functional status, ideally norm-referenced with a percentile ranking; and
- Sub-scores for different activities or activity areas to provide a profile of functional strengths and weaknesses. Activity areas are defined by the World Health Organization and other key stakeholders as [41]:
  - Learning and applying knowledge [42]
  - General tasks and demands [43-52]
  - Communication [47, 48, 51-53]
  - Mobility [47, 48, 53, 54]
  - Self-care [47-54]
  - Domestic life [47, 49-52]
  - Interpersonal interactions and relationships [27, 29, 47, 49-53]
  - Major life areas [27, 29, 42, 47, 49, 50, 53]
  - Community, social and civic life [47, 49-52].

The tools with the greatest evidence-base for use with individuals with ASD are:

1. The ICF Core Sets for ASD [55-58] in combination with the WHO-DAS 2.0 [47]. The ICF core-sets for ASD are due for publication at the end of 2017, and the web resources for the diagnostic guideline will be updated with templates, links and other instructional materials once the final ICF Core Sets for ASD are published.
2. Vineland Adaptive Behavior Scales, Second or Third Editions [51, 52];
3. Adaptive Behaviour Assessment Systems, Second or Third Editions [49, 50].
4. The Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT, [59]). Please not that administration of the PEDI-CAT is restricted to children, adolescents and young adults (up to 21 years of age).

## CBR-2

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

An individual's strengths in relation to their activity related and character strengths can be determined through the following means:

- Providing Consumers with a list of the ICF Core Sets for ASD (Web Resources, [55-58]), and asking them to select the activities where they feel they have the strongest skills;
- Asking the Consumer open-ended questions that seek to elicit their perspective of key strengths; and/or
- Character strengths can be identified through the administration of the free online self-report measure, *VIA Character Strengths Survey* (Table 9, [60, 61]).

**Table 9. Types of activity related and character strengths**

Commonly Reported ASD-Specific Strengths [56]	General Strengths [60]
<p><b>Activity Related Strengths:</b></p> <ul style="list-style-type: none"> <li>• <b>Attention to detail</b></li> <li>• <b>Expertise in a specific area</b></li> <li>• <b>Mathematical abilities</b></li> <li>• <b>Creative talents</b></li> <li>• <b>Look at the world differently</b></li> <li>• <b>Artistic skills</b> <ul style="list-style-type: none"> <li>○ Music</li> <li>○ Drawing and visual arts</li> </ul> </li> <li>• <b>Visual perception</b></li> <li>• <b>Intellectual functions</b></li> <li>• <b>Technical abilities</b> <ul style="list-style-type: none"> <li>○ Computer skills</li> <li>○ Engineering</li> </ul> </li> </ul> <p><b>Character Strengths:</b></p> <ul style="list-style-type: none"> <li>• <b>Strong sense of morality</b> <ul style="list-style-type: none"> <li>○ Honesty</li> <li>○ Lack of judgmental attitude</li> </ul> </li> <li>• <b>Trustworthiness</b></li> <li>• <b>Loyalty</b></li> </ul>	<p><b>Character Strengths:</b></p> <p><i>Wisdom and Knowledge</i></p> <ul style="list-style-type: none"> <li>• Creativity</li> <li>• Curiosity</li> <li>• Love of Learning</li> <li>• Judgement</li> <li>• Perspective</li> </ul> <p><i>Courage</i></p> <ul style="list-style-type: none"> <li>• Bravery</li> <li>• Perseverance</li> <li>• Honesty</li> <li>• Zest</li> </ul> <p><i>Humanity</i></p> <ul style="list-style-type: none"> <li>• Love</li> <li>• Kindness</li> <li>• Social Intelligence</li> </ul> <p><i>Justice</i></p> <ul style="list-style-type: none"> <li>• Teamwork</li> <li>• Fairness</li> <li>• Leadership</li> </ul>

- **Kindness**

*Temperance*

- Forgiveness
- Humility
- Prudence
- Self-Regulation

*Transcendence*

- Appreciation of Beauty and Excellence
- Gratitude
- Hope
- Humour
- Spirituality

**CBR-2**

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

The impact of the individual's current physical, social and institutional environments on their functioning can be determined through:

- Completing the Environmental Factors section of the ICF Core Sets for ASD (Web Resources, [55-58]), where ratings can be assigned on a five-point scale for both facilitators and barriers;
- Reviewing responses to the Activity and Participation section of the ICF Core Sets for ASD (Web Resources, [55-58]) with the Consumer, and asking whether environmental factors help or hinder the individual in their performance of any of these activities.

Information about the individual's interaction between their function and environment within all relevant community settings may be obtained through a combination of:

- Direct observation of the individual in natural environments;
- Review of video recordings of the individual in natural environments; and/or
- Verbal or written report (including file review) from the Consumer, Diagnostician(s) and/or Professional Informant(s).

## 10.4 Support Needs Assessment

### 10.4.1 Professional Involvement

CBR-2

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]

A Functional and Support Needs Assessor may be:

- A Diagnostician or Professional Informant who was involved in the Diagnostic Evaluation; or
- An individual who meets requirements to be either a Diagnostician or Professional Informant, but who was not involved in the Diagnostic Evaluation.

### 10.4.2 Settings

The Support Needs Assessment should take place in a private and comfortable setting where the Consumer feels confident to discuss their needs. This may be in a clinic or community setting. Information must be collected about the individual's support in relation to all relevant community settings, although it is not essential to visit these locations.

CBR-2

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]

### 10.4.3 Information Collection

Information collected from a variety of sources can greatly assist the development of a comprehensive functional picture of an individual. These include:

- File review of existing assessment reports;
- Interview with the Consumer;
- Observation of the individual;
- Communication with Professional Informant(s); and/or
- Standardised assessments.

The Support Needs Assessment should identify potential:

- **Observed needs to maintain current supports** that facilitate function. These can be ascertained through consumer ratings and/or interview based on ICF Core Sets for ASD (Web Resources), where it is identified that current activity performance levels are only possible due to existing supports and the individual's capacity would be reduced if these existing supports were no longer available. The presence of an environmental facilitator on this form would also suggest an observed need in relation to maintaining current supports.
- **Observed needs to increase supports** to allow functional status to improve. These can be ascertained through consumer ratings and/or interview based on ICF Core Sets for ASD (Web Resources), where it is indicated that potential activity participation exceeds current activity performance. The presence of an environmental barrier on this form would also suggest an observed need in relation to increasing supports.
- **Expressed needs** for further supports, as identified during conversations with the Consumer through active listening, direct questioning and/or during an assessment of goals.

These potential support needs can then be prioritised by the Consumer, by choosing and/or ranking a set number of support needs. The next step involves assisting the consumer to develop set related goals.

CBR-1

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

The Functional and Support Needs Assessor can provide guidance on the type of supports that will assist the individual and/or their caregivers to address these prioritised support needs and goals through overcoming limitations / barriers and optimising strengths / facilitators. Where required to access a service, the Functional and Support Needs Assessor can make a referral to appropriate service providers to ensure these supports are implemented. These supports may include (but are not limited to):

- Information booklets and other resources to review independently;
- Informal social networks (face-to-face or online);
- Formal social or support groups;
- Self-directed intervention programs; and/or
- Individual or group intervention programs with allied health or educational professionals.

It is beyond the scope of a Support Needs Assessment to conduct specific assessments required to establish specific intervention goals. This is the responsibility of the clinician(s) that will provide ongoing clinical management of the individual.

CBR-1

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

## 10.5 Repeated Assessment

CBR-1

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]

Repeated administration of the Functional and Support Needs Assessment will facilitate Consumers receiving the most appropriate supports within a lifespan approach, particularly around assisting to prepare for, and progress through, major transitional periods (e.g. into pre-primary or into the workplace). An individual's functional status and support needs are a product of the interaction between their clinical symptoms, activity demands, and personal and environmental factors at that particular time, and so functional status and support needs will fluctuate across an individual's lifetime. Timing of the next assessment is to be mutually agreed by the Consumer and Functional and Support Needs Assessor.

# 11 SHARING ASD ASSESSMENT FINDINGS

## 11.1 Communication Style

Findings from the ASD assessment should be disclosed to the individual who underwent assessment and/or their caregiver (as appropriate based on age and communication abilities), in a way they understand and is meaningful.

Findings from both the Diagnostic Evaluation and the Functional and Support Needs Assessment should initially be shared during face-to-face meeting(s). If geographical location or travel restrictions makes a face-to-face meeting logistically difficult, then this meeting may occur via telephone or videoconferencing. In this situation, it is recommended that a Professional Informant from the local community is physically present with the Consumer during the meeting.

The findings should also be outlined in a written report, which may either be one document that combines information from the Diagnostic Evaluation and the Functional and Support Needs Assessment, or in two separate reports (see Web Resources for templates). Provision of this report to the Consumer would ideally occur within three months of the first appointment as part of the ASD assessment process.

These meeting(s) and written report(s) are to be:

- Comprehensive and informative;
- Sensitive and emotionally supportive in nature;
- Worded in language suitable for a layperson audience (i.e. jargon is either excluded or clearly defined);
- Assisted by an interpreter and/or translator if required; and
- Conducted as soon as logistically possible after the last assessment appointment.

CBR-1

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]

## 11.2 Content of Communication

CBR-1

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;
- Alternative 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]

# 12 IMPORTANT CONSIDERATIONS

## 12.1 Age

The behaviours that characterise ASD are known to vary according to age, and also fluctuate within the same individual over time. An important principle is to base an ASD assessment within a developmental framework, in which an individual is evaluated against what would be expected by typically developing peers of the same age. The following three tables provide information regarding key considerations for assessments of preschool-aged children (Table 10), school-aged children (Table 11), and older adolescents / adults (Table 12).

**Table 10. Additional considerations for preschool children (ages 0 to 5 years)**

Aspect	Considerations
<b>Signs and Symptoms</b>	<p>There is now robust empirical evidence that ASD can be reliably and validly diagnosed at 2 years of age by an experienced clinician, and that this diagnosis is relatively stable over time [62, 63]. However, the most common age of ASD diagnosis in Australia is between 3 and 5 years of age [64].</p> <p>A list of some of the key signs and symptoms of ASD in early childhood are listed below [2]. This list is intended to provide guidance about commonly reported signs and symptoms for ASD in the pre-school years, and is not an exhaustive list. An assessment of whether there is a reduction in the frequency or variety of a particular behaviour, should be made in comparison with peers of the same age, gender and cognitive ability.</p> <p><b>Spoken Language</b></p> <ul style="list-style-type: none"> <li>• Language delay in babble or words</li> <li>• Reduced use of language for communication</li> <li>• Regression in speech and language skills</li> <li>• Frequent repetition of certain words or phrases ('echolalia')</li> </ul> <p><b>Responding to others</b></p> <ul style="list-style-type: none"> <li>• Absent or delayed response to name being called (assuming adequate hearing)</li> <li>• Reduced responsiveness to social smiling</li> </ul> <p><b>Interacting with others</b></p> <ul style="list-style-type: none"> <li>• Reduced social interest in others</li> <li>• Reduced imitation of others' actions</li> <li>• Reduced initiation of social play with others</li> <li>• Reduced enjoyment of situations that most children like (e.g., birthday parties).</li> <li>• Reduced sharing of enjoyment with others</li> </ul> <p><b>Eye-contact, pointing and other gestures</b></p>

	<ul style="list-style-type: none"> <li>• Reduced use of gestures and facial expressions to communicate with others</li> <li>• Reduced social use of eye contact (assuming adequate vision)</li> <li>• Reduced pointing or showing objects to share interest</li> </ul> <p><b>Play</b></p> <ul style="list-style-type: none"> <li>• Reduced use of pretend play</li> </ul> <p><b>Restricted interests and/or rigid and repetitive behaviours</b></p> <ul style="list-style-type: none"> <li>• Repetitive movements, such as hand flapping, spinning, and finger flicking</li> <li>• Repetitive play</li> <li>• Over-focused or unusual interests</li> <li>• Excessive insistence on following own agenda</li> <li>• Over or under reaction to sensory stimuli (e.g., textures, sounds, smells, taste).</li> <li>• Pathological Demand Avoidance is a subtype of ASD that is recognised in the United Kingdom. It is typified by an avoidance of everyday demands and expectations to an extreme extent, and is driven by an anxiety-based need to be in control. Typical signs/symptoms include the resistance or avoidance of ordinary demands of life, and the use of social strategies as part of the avoidance (e.g., distracting or giving excuses).</li> </ul>
<b>Information Collection</b>	<p>Both DSM and ICD diagnostic criteria state that ASD symptoms must be present during early childhood, and so an assessment during this age period provides an opportunity for direct observation of these behaviours at this time.</p> <p>Typically, the main environments in which young children interact are with the immediate family within the family home. Collection of additional information from individuals who may regularly observe the child in this setting (e.g. primary caregivers, siblings, grandparents) will provide critical information to guide the assessment. Additional information from professionals who may observe the child in the home or outside settings may also be valuable, such as Child Health Nurses, Child Care Educators, and General Practitioners.</p>
<b>Sharing Findings</b>	<p>Discuss with parents or caregivers how they would like the diagnostic decision communicated, including with their child, taking into account the child’s ability to understand this information. Use clinical judgment in guiding parents through these decisions.</p>
	<p>The receipt of an ASD diagnosis may elicit a range of reactions. Negative reactions can include shock, disappointment, loss, anger, as well as concerns about stigma and other negative reactions from others. Positive reactions can include the feeling that a diagnosis has provided an explanation and understanding of the behaviours and previous experiences of the individual. Reactions to the diagnosis may have an influence on future clinical management of the individual, and so it is critical that all professionals involved in the ASD assessment have an understanding of the personal effect of the outcome of an ASD assessment.</p>

**Table 11. Additional considerations for school-aged children (ages 6 to 16 years)**

Aspect	Considerations
<b>Signs and Symptoms</b>	<p>A significant number of children are not recognised as having ASD until the school years [65], when the social and communication demands placed on the child are significantly increased.</p> <p>A list of some of the key signs and symptoms of ASD in middle childhood are listed below [2]. This list is intended to provide guidance about commonly reported signs and symptoms for ASD in the school years, and is not an exhaustive list. An assessment of whether there is a reduction in the frequency or variety of a particular behaviour, should be made in comparison with peers of the same age, gender and cognitive ability.</p> <p><b>Spoken language</b></p> <ul style="list-style-type: none"> <li>• Spoken language may be unusual in several ways:</li> <li>• Very limited use</li> <li>• Monotonous in tone</li> <li>• Repetitive language, with frequent use of certain phrases, or with content dominated by excessive information on topics of interest.</li> <li>• Talking ‘at’ others rather than a two-way conversation</li> </ul> <p><b>Responding to others</b></p> <ul style="list-style-type: none"> <li>• Reduced response to other’s facial expressions</li> <li>• Reduced response to name being called (assuming adequate hearing)</li> </ul> <p><b>Interacting with others</b></p> <ul style="list-style-type: none"> <li>• Reduced social interest in others</li> <li>• Reduced awareness of socially expected behaviour</li> <li>• Reduced ability to share in the social play of others</li> <li>• Reduced enjoyment of situations that most children like</li> </ul> <p><b>Eye-contact, pointing and other gestures</b></p> <ul style="list-style-type: none"> <li>• Reduced or poorly integrated use of gestures, facial expressions and eye contact during social communication with others (assuming adequate vision)</li> <li>• Reduced pointing or showing objects to share interest</li> </ul> <p><b>Play</b></p> <ul style="list-style-type: none"> <li>• Reduced variety and flexibility in imaginative play</li> </ul> <p><b>Restricted interests and/or rigid and repetitive behaviours</b></p> <ul style="list-style-type: none"> <li>• Repetitive movements, such as hand flapping, spinning, and finger flicking</li> <li>• Repetitive play and focused on objects rather than people</li> <li>• Over-focused or unusual interests</li> </ul>

	<ul style="list-style-type: none"> <li>• Excessive insistence on following own agenda</li> <li>• Strong preference for familiar routines</li> <li>• Over or under reaction to sensory stimuli (e.g., textures, sounds, smells, taste).</li> </ul>
<b>Information Collection</b>	<p>The older a child is at the time of a diagnostic evaluation, the more information there will be for a Diagnostician to review. Sources of information may include previous clinical assessments or intervention reports, school and medical records, and any other observations collected by the caregivers across early childhood.</p> <p>Children of this age will also have had more interaction with individuals and the environment outside of the family and the home, which provides an opportunity to obtain further information about child behaviour in other settings [66].</p>
<b>Sharing Findings</b>	<p>Discuss with parents or caregivers how they would like the diagnostic decision communicated, including with their child, taking into account the child's ability to understand this information. Use clinical judgment in guiding parents through these decisions.</p>
	<p>The receipt of an ASD diagnosis may elicit a range of reactions. Negative reactions can include shock, disappointment, loss, anger, as well as concerns about stigma and other negative reactions from others. Positive reactions can include the feeling that a diagnosis has provided an explanation and understanding of the behaviours and previous experiences of the individual. Reactions to the diagnosis may have an influence on future clinical management of the individual, and so it is critical that all professionals involved in the ASD assessment have an understanding of the personal effect of the outcome of an ASD assessment.</p>

**Table 12. Additional considerations for older adolescents and adults (ages 17 years and older)**

<b>Aspect</b>	<b>Considerations</b>
<b>Signs and Symptoms</b>	<p>While ASD is most commonly diagnosed in childhood, the signs and symptoms of the condition can sometimes go unrecognised until adolescence and adulthood.</p> <p>A list of some of the key signs and symptoms of ASD in older adolescents and adults [1, 2] are listed below. This list is intended to provide guidance about commonly reported signs and symptoms for ASD for these age groups, and is not an exhaustive list. An assessment of whether there is a reduction in the frequency or variety of a particular behaviour, should be made in comparison with peers of the same age, gender and cognitive ability.</p> <p><b>Spoken language</b></p> <p>Spoken language may be unusual in several ways:</p>

- Very limited use
- Monotonous in tone
- Repetitive language, with frequent use of certain phrases, or with content dominated by excessive information on topics of interest.
- Talking 'at' others rather than a two-way conversation
- Difficulty with 'small talk'
- Bluntness

#### **Interacting with others**

- Long standing difficulties in reciprocal social communication and interaction
- Reduced understanding of friendship
- Reduced awareness of socially expected behaviour, including personal space
- Social isolation and apparent preference for aloneness

#### **Eye-contact, pointing and other gestures**

Reduced, atypical or poorly integrated use of gestures, facial expressions and eye contact during social communication with others (assuming adequate vision)

#### **Play**

History of a lack of flexible social imaginative play

#### **Restricted interests and/or rigid and repetitive behaviours**

- Repetitive movements, such as hand flapping, spinning, and finger flicking
- Preference for highly specific interests or hobbies
- Strong preference for familiar routines that may lead to emotional distress if the routine is disrupted
- Difficulty multitasking
- Over or under reaction to sensory stimuli (e.g., textures, sounds, smells, taste).

Common manifestations of these signs and symptoms, include:

- Problems in obtaining or sustaining employment or education;
- Difficulties in initiating or sustaining social relationships;
- Previous or current contact with mental health or learning disability services;
- A history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or psychiatric difficulties.

#### **Information Collection**

The older an individual is, the more challenging an appraisal of their early medical and developmental history can be. While all efforts should be made to obtain this information, either through self/informant report and/or the evaluation of archived records, it is possible the information may not be available. The absence of this

	<p>information magnifies the importance of the appraisal of current signs and symptoms, and it is critical to collect information from a range of settings and sources that are relevant to the chronological age of the individual. This includes the use of psychometric tests that have been designed for the assessment of ASD symptoms, cognitive abilities and support needs for adolescents and adults.</p> <p>If an individual is presenting for an ASD assessment during adulthood (18 years of age or older), it is possible that they may be legally responsible for their own health care (see 12.2 for further guidance). In these circumstances, it is important to ask the individual how they may like their families, partners or carers to be involved in their assessment and care. If the person would like their family, parent(s) or carer(s) involved, then discuss with the person about confidentiality and sharing of clinical information into the future [1].</p>
	<p>Diagnosticians and Functional and Support Needs Assessors should ensure that procedures are modified to the setting in which the assessment is delivered, and the cognitive capacity and emotional resilience of the individual being assessed.</p> <p>It is well-established that a range of mental health conditions are common among autistic adolescents and adults, including major depressive disorder and anxiety disorders, such as social anxiety disorder and obsessive-compulsive disorder. It is critical in the evaluation of symptomatology and functional difficulties, as well as in the understanding of support planning, to provide an adequate evaluation of mental health functioning.</p>
<p><b>Sharing Findings</b></p>	<p>If the individual being assessed is able to understand verbal language, then discuss with this person how they may like the diagnostic decision communicated, including with any family members or carers.</p> <p>The receipt of an ASD diagnosis may elicit a range of reactions. Positive reactions can include the feeling that a diagnosis has provided an explanation and understanding of the behaviours and previous experiences of the individual. Negative reactions can include shock, disappointment, loss, anger, as well as concerns about stigma and other negative reactions from others. Reactions to the diagnosis may have an influence on future clinical management of the individual, and so it is critical for the Diagnostician to have an understanding of the personal effect of the diagnostic evaluation decision.</p> <p>The type of services required for the appropriate clinical management of autistic adolescents and adults, as well as accessibility to clinical and support services, is likely to be different to those for autistic children. Prior to undertaking any diagnostic evaluation of adolescents or adults, a professional within the diagnostic team must have a good understanding of the clinical pathway for these individuals, and the clinical and support services they may be eligible to access.</p>

**CBR-1**

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]

## 12.2 Intellectual and / or Communication Capacity

'Intellectual disability' refers to individuals who have a significant impairment in cognitive and adaptive abilities, usually confirmed with a score on a standardised IQ test of 70 or less. 'Minimal verbal language' refers to individuals who have little to no spoken language that is used spontaneously for communication. Approximately 30% of individuals that receive a diagnosis of ASD have intellectual disability [67, 68], and 30% have minimal verbal language [69]. However, it is incorrect to assume that these figures indicate complete overlap in individuals: the absence of verbal language should not be interpreted as reflecting intellectual disability, and the presence of verbal language should not be used to rule out intellectual disability. Recent research has indicated that commonly used IQ tests, such as the Wechsler Intelligence Scale for Children, may underestimate the cognitive ability of autistic children with ASD who have minimal verbal language [70].

It is critical for Diagnosticians and Professional Informants to have a good understanding of the limitations of some standardised cognitive and communication assessments in the accurate appraisal of the ability of individuals with minimal verbal ability, and to identify the most appropriate assessments based on the behavioural presentation of the individual [71].

The presence of intellectual disability and/or minimal verbal language provides the additional concern of whether an individual provides consent for their own health and medical care. Consent is considered valid if it is provided freely and without duress, by an individual who is legally capable of providing consent, and who is fully informed about what they are providing consent for. In general, Australian law recognises that an individual aged 18 years or over has full legal capacity, and is capable of making decisions regarding their own healthcare. However, even if an individual is at least 18 years of age, the presence of intellectual ability and/or minimal verbal language raises the concern that this individual may not be sufficiently capable of making informed choices about a health care procedure, such as an ASD assessment. A general framework for assessing capability is to appraise whether an individual has:

- An ability to comprehend and retain information; and
- Weigh that information in the balance to arrive at a choice [72].

In instances in which an adult is not deemed to have the capacity to consent to the ASD assessment, each Australian state and territory has guardianship legislation that enables consent to be provided from a substitute decision maker (Table 13).

Please note that this information is intended as a guide only and should not be taken as legal advice. For more complete guidance, contact your professional body, indemnity provider or a legal representative.

**Table 13. Guardianship legislation in each state and territory of Australia**

State	Legislation
Australian Capital Territory	Guardianship and Management of Property Act 1991
New South Wales	Guardianship Act 1987
Northern Territory	Guardianship and Administration Act 1988

Queensland	Guardianship and Administration Act 2000
South Australia	Guardianship and Administration Act 1993
Tasmania	Guardianship and Administration Act 1995
Victoria	Guardianship and Administration Act 1986
Western Australia	Guardianship and Administration Act 1990

### CBR-1

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]

## 12.3 Gender

ASD is diagnosed more commonly in males than females [73, 74], with an often reported male:female ratio of 4:1 [74, 75]. However, there is accumulating evidence that this male preponderance may not be a reflection of the true gender ratio of ASD, but represent a bias towards males in the diagnostic process. Several studies have found that boys are more likely to be identified with ASD than girls, even when symptoms are equally severe [76]. There is also evidence that females are better able to 'camouflage' their symptoms and use compensatory strategies to mitigate communication and social difficulties [77, 78]. Furthermore, the diagnostic criteria for ASD, and the instruments used to assess these behaviours, reflect a presentation that is more common in males than females [75], and may not have adequate sensitivity and specificity to identify ASD characteristics in females [79]. For example, autistic females are more likely than autistic males to have less frequent and severe repetitive behaviours and stereotypies [80] and use a greater range and frequency of nonverbal (gestural) communication [81], particularly amongst individuals without intellectual disability.

Symptom differences between genders has been raised as one factor that may contribute to a later age of diagnosis amongst autistic females [81]. Given the importance of early diagnosis and intervention in promoting more positive longer-term outcomes in autistic children, an understanding of how ASD may manifest differently between genders remains critically important.

### CBR-1

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]

People who are trans or gender diverse identify with a gender identity that does not match their sex assigned at birth. Gender dysphoria refers to the distress over the incongruence of

one's gender identity and sex assigned to them at birth. While not all trans people are gender dysphoric, it is common for these individuals to be diagnosed with gender dysphoria within a clinical setting. There is accumulating evidence that trans or gender diversity is more common in autistic children, adolescents and adults compared to the broader population [82].

While the evidence base does not currently warrant the recommendation for universal screening of gender diversity in ASD diagnostic evaluations, the identification of this co-occurrence should trigger a referral to appropriate services with expertise in gender diversity [83]. Sensitivity should be used in relation to gender related language during the ASD assessment. This may be achieved in part through allowing individuals to self-describe their gender on initial intake forms and avoiding gender related pronouns (e.g. he, she).

CBR-2

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]

## 12.4 Culturally and Linguistically Diverse (CALD) Backgrounds

There is evidence that individuals from racial and/or ethnic minorities are, on average, diagnosed with ASD later than the broader population [84-87]. It remains unclear whether this disparity is due to differences in access to diagnostic services, clinicians' and/or families' interpretation of symptoms, or other institutional factors [86]. The vast majority of published research has concentrated on families with European heritage, and little is understood about whether symptom expression varies by cultural background, and whether there are support services that may be more acceptable, feasible and effective for individuals and families from different racial or ethnic backgrounds.

It is important that professionals maintain frank self-awareness about any lack of knowledge they may have about a particular culture, such as:

- Child-rearing practices, interpretation of how children play with adults and each other, and the expectations of families and caregivers about child development [2];
- Whether there may be any cultural stigma attached to disability;
- The appropriateness of the information collection strategies (including psychometric tests) in obtaining the best understanding of the individual's clinical symptoms, and functional and support needs. This may include conducting the assessments in the first language of the individual being assessed.
- Clear and nuanced communication is a critical part of any clinical interaction, facilitating the adequate communication of the requirements of the interaction, collecting sufficient and accurate information, and to conveying the outcome of the assessments.

CBR-1

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]

CBR-1

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]

CBR-1

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]

Particularly relevant to Australia is the provision of clinical services to Aboriginal peoples by practitioners who are not Aboriginal and/or Torres Strait Islander people. Very little research has investigated ASD in Aboriginal peoples, though there is preliminary evidence that ASD may be underdiagnosed in Aboriginal population groups [88]. Considerations for working with Aboriginal peoples include [32]:

- Acknowledge and empower the role of the family, extended family and community in the provision of services. Practitioners and other workers may need to identify attitudes and beliefs that the individual and family have with regards to ASD before undertaking any clinical activities.
- Provide the necessary and appropriate education for Aboriginal peoples who may be vulnerable to misunderstanding the purpose of the ASD assessment. Material written in English is not culturally appropriate for Aboriginal peoples who use their oral tradition, and understanding the nuanced messages that form an ASD assessment may require too high a proficiency in written English. Written material should be produced in the relevant language, and language interpreters should be offered, regardless of perceived proficiency in English.
- Use of standardised tests should be used with significant caution, given that Aboriginal peoples have often not been well-represented in the study samples on which standardised norms are generated. It is critical that an appraisal of any clinical symptoms is based in an understanding of cultural values and traditions, and the ecological context in which the individual lives.
- Involve Aboriginal Health Workers, carers, teacher aides, cultural workers and/or clinicians from the receipt of referral through to the communication of assessment findings and connection of the family to support services. While the involvement of these individuals in the ASD assessment process is ideal, there may be times when

this is not feasible. The successful completion of cultural competency training should be a minimum requirement for conducting ASD assessments in these instances.

Given the lack of research in the area of ASD and Aboriginal peoples, these considerations reflect only a starting point for the sector.

CBR-2

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]

CBR-1

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]

## 12.5 Regional or Remote Location

On average, children living in rural communities receive a diagnosis of ASD later than those living in urban communities [3, 84], which has been attributed to a relative lack of identification and diagnostic services in regional and remote settings [3]. In these settings, there may not be any medical or health professionals with clinical expertise in ASD, and in some remote settings, a relevant medical or health professional may only visit the community a limited number of times each year.

CBR-1

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]

CBR-1

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]

## 12.6 Differential Diagnosis and Co-occurring Conditions

It is well established that the behavioural symptoms that define ASD are often observed in individuals with other clinical conditions, and that autistic individuals often present with symptoms that are characteristic of other clinical conditions. Differential diagnosis is the distinguishing of a particular disorder from other disorders that may present with similar clinical symptoms. Comorbidity is the presence of two or more distinct disorders in the same individual. Table 14 presents information on common differential disorders and co-occurring conditions in ASD.

<b>Table 14. Differential diagnosis and co-occurring conditions</b>		
<b>Condition</b>	<b>Differential diagnosis</b>	<b>Co-occurring condition</b>
<b>Psychiatric and neurodevelopmental disorders</b>		
Attention-deficit/hyperactivity disorder	✓	✓
Intellectual disability	✓	✓
Language Disorders	✓	✓
Social (pragmatic) communication disorder	✓	
Stereotypic movement disorder	✓	✓
Tic disorders	✓	✓
Anxiety disorders	✓	✓
Conduct disorder	✓	✓
Major depressive disorder	✓	✓
Obsessive compulsive disorder	✓	✓
Personality disorders	✓	✓
Reactive attachment disorder	✓	
Schizophrenia	✓	✓
Selective mutism	✓	✓
<b>Neurological and other medical conditions</b>		
Epilepsy		✓
Landau Kleffner syndrome	✓	
Neonatal encephalopathy		✓
Cerebral Palsy	✓	✓
Mitochondrial disorders	✓	✓
<b>Genetic conditions</b>		
Angelman syndrome		✓
Cornelia deLange syndrome		✓
Down syndrome		✓
Fragile X syndrome	✓	✓
Lesch-Nyhan syndrome		✓
Prader-Willi syndrome	✓	✓
Rett Syndrome	✓	

Smith-Lemli-Opitz syndrome		✓
Tuberous sclerosis		✓
Williams Syndrome		✓
<b>Environmental factors</b>		
Fetal alcohol spectrum disorder	✓	✓
Phenylketonuria (PKU)	✓	✓
<b>Other conditions</b>		
Vision impairment	✓	✓
Hearing impairment	✓	✓
Developmental coordination disorder	✓	✓

## 12.6.1 Differential Diagnosis

There are a range of genetic, psychiatric and neurodevelopmental conditions that have one or more symptoms that are similar to ASD, but which are not ASD. Table 15 presents alternative clinical conditions that can present with symptoms that may overlap with the ASD diagnostic criteria [66].

At each stage of the Diagnostic Evaluation, it is critical for the Diagnostician to use the information collection techniques described in 9.4.3 and 9.5.3 to consider the full range of clinical explanations for symptom presentation, and test these possible explanations against the evidence for an ASD diagnosis.

**Table 15. Genetic, psychiatric and neurodevelopmental conditions that may have an overlapping symptom profile with ASD (with diagnostic manual in which these conditions are described)**

ASD symptom	Other potential clinical explanation
<b>Clinical differences in language and/or communication</b>	Language disorder (DSM-5)
	Expressive language disorder (ICD-10)
	Mixed receptive-expressive language disorder (ICD-10)
	Speech sound disorder (DSM-5)
	Phonological disorder (ICD-10)
	Social (pragmatic) communication disorder (DSM-5 and ICD-10)
	Selective mutism (DSM-5 and ICD-10)
<b>Clinical differences in social interaction</b>	Attention-deficit/hyperactivity disorder (DSM-5 and ICD-10)
	Anxiety disorders, particularly social anxiety disorder (DSM-5) and social phobia (ICD-10).
	Major depressive disorder (DSM-5 and ICD-10)

	Personality disorders (DSM-5 and ICD-10)
<b>Clinical differences in restricted interests and repetitive behaviours</b>	Stereotypic movement disorder (DSM-5 and ICD-10)
	Obsessive compulsive disorder (DSM-5 and ICD-10)
	Tic disorders, including Tourette syndrome (DSM-5 and ICD-10)
<b>Clinical differences in multiple areas of functioning</b>	Intellectual disabilities (DSM-5 and ICD-10)
	Global developmental delay (DSM-5)
	Reactive attachment disorder (DSM-5 and ICD-10)
	Schizophrenia (DSM-5 and ICD-10)
	Traumatic brain injury (DSM-5 and ICD-10)
	Neurobehavioural Disorder Associated with Prenatal Alcohol Exposure (DSM-5 appendix)
	Fetal alcohol syndrome (ICD-10)
	Genetic syndromes, such as Rett Syndrome and Williams Syndrome

### CBR-1

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]

## 12.6.2 Co-occurring Conditions

It is critical to recognise that the presence of ASD does not preclude an individual also having a range of other conditions. A number of psychiatric, neurodevelopmental, neurological, medical and genetic conditions are known to co-occur with ASD at higher than expected rates [89, 90]. These co-occurring conditions can either be secondary to the experience of having ASD (e.g., mood or anxiety disorders arising in response to the effects of social interaction difficulties), or co-exist as part of an ASD (e.g., intellectual disability) [91]. Prevalence data from a range of countries have been reviewed previously, and the pooled prevalence for these studies are reported in Table 16 [2].

**Table 16. Pooled prevalence data indicating the proportion of autistic individuals that have a range of coexisting conditions [91]**

Conditions	Estimated prevalence
<b>Psychiatric and neurodevelopmental conditions</b>	
Attention-deficit/hyperactivity disorder	45%

Intellectual disability	30%
Anxiety disorders	27%
Oppositional defiant disorder	23%
Tic disorders (including Tourette syndrome)	19%
Tourette syndrome	12%
Depression	9%
Obsessive compulsive disorder	8%
Conduct disorder	3%
Pathological demand avoidance	No estimate available
<b>Neurological or medical conditions</b>	
Gastrointestinal problems	30%
Motor problems	25%
Epilepsy	15%
Seizures	5%
Cerebral palsy	5%
<b>Genetic conditions</b>	
Angelman syndrome, Cornelia deLange syndrome, Down syndrome, Fragile X syndrome, Lesch-Nyhan syndrome, Prader-Willi syndrome, Smith-Lemli-Opitz syndrome, Tuberous sclerosis or other genetic conditions	15%  (for any of these conditions)
<b>Other conditions</b>	
Sleep disorders	61%
Auditory deficits	8%
Vision deficits	6%

### CBR-1

Diagnostician 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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