



Neurodevelopmental and Behavioural
Paediatric Society of Australasia

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19 October 2017

Professor Andrew Whitehouse
Chair, Research Executive Team
Draft National Guideline, Autism Spectrum Disorder Diagnosis
Autism CRC.
via email: info@autismcrc.com.au

Dear Andrew,

Please find the Neurodevelopmental and Behavioural Paediatric Society of Australasia (NBPSA) response to the draft national guideline for diagnosis of Autism Spectrum Disorder.

We welcome the opportunity for collaboration that this work has created and are pleased to support efforts to promote greater national consistency and accuracy in the diagnostic and functional needs assessment of neurodevelopmental and behavioural conditions, including Autism Spectrum Disorder.

We have significant concerns that implementation of the current recommendations will lead to greater variation in diagnostic outcomes and higher exposure to clinical risk generally, as well as increase the chance of sub-optimal developmental outcomes for some children. Accordingly, we cannot support the guideline in its current form.

As noted in the Technical Paper, the paucity of evidence in this area led to development of a unique methodology for evaluating and applying available evidence. We have identified significant concerns with the approach devised and strongly suggest that the methodology be independently reviewed. We will provide more detail in a separate submission on the Technical Report and Evidence Tables to assist your consideration of this issue.

We are also concerned that the draft guideline may promote a proliferation of Autism specific assessment services. We feel strongly that ASD assessments should occur within existing systems and pathways for assessing neurodevelopmental and behavioural concerns. Autism specific assessment services can only serve to duplicate or disperse the already limited assessment resources available and, as described in our response, increase the risk of error in differential diagnosis and identification of co-morbidities.

We have contributed to the RACP response to the guidelines and consulted with RANZCP and RACGP and would like to work with the Autism CRC in developing a constructive way forward, particularly in building expert consensus for issues where there is a lack of conclusive evidence.

We provide this response directly, rather than through the public portal and seek your response and the opportunity to discuss the next steps before further guideline development or public consultation is undertaken. Please contact me on Gehan.roberts@rch.org.au, or our Chief Executive Officer, Greg Rochford, on g.rochford@nbpsa.org or 0412 196 172.

Yours sincerely,

Associate Professor Gehan Roberts
President



Response to the draft national guideline for assessment of Autism Spectrum Disorder

Introduction:

The NBPSA comprises doctors, primarily paediatricians, with clinical expertise and specialist interests in neurodevelopmental and behavioural concerns in children and young adults (typically 0-18 years). Our feedback is focused on the care, assessment and diagnosis of individuals in this age group, who have specific diagnostic needs. The majority of individuals diagnosed with ASD each year in Australia are aged below 18 years, and Paediatricians make the vast majority of these diagnoses¹

We support the need for greater national consistency and accuracy in diagnostic and functional needs assessment of neurodevelopmental and behavioural conditions, including ASD. We welcome the guiding principles that have been developed for the draft guideline. However, the NBPSA cannot support the draft guideline in its current form. We are concerned that implementation of the current draft guideline recommendations will lead to greater variation in diagnostic outcomes and higher exposure to risk.

Although outside the scope of guideline development, we are particularly concerned about the implications of these guidelines in the current Australian context, where ASD diagnosis is used as a criterion for eligibility for funding and support for health, education and disability services. NBPSA strongly supports access to support based on function and support needs, rather than access based on specific diagnostic labels such as ASD.

Key concerns arising from our review of the draft guideline include the following:

- The presumption that ruling in or ruling out a diagnosis of ASD is the primary outcome for a child who has been referred for assessment due to complex developmental and behavioural concerns.
- The evidence, as presented, is insufficient to justify a number of recommendations which could, if executed, have major impacts on diagnostic process and accuracy. Such recommendations require a high level of evidence or a clear, accepted rationale of risks, benefits and cost, neither of which are provided.
- The two-tier structure as proposed will increase diagnostic error and may further overload existing assessment services. While we support a staged approach to neurodevelopmental and behavioural assessment, based on individual need and complexity, further consultation and consideration is required.
- The recommendations do not take in to account existing services and 'pathways to care' and may place additional pressure on families and carers to pursue assessments outside existing publicly funded arrangements, as well as making implementation difficult and expensive.
- Although the importance of subgroups is recognised in the guideline, there is no adaptation to the diagnostic pathways to cater to the very different diagnostic processes required for children and youth, given the careful consideration that is needed when making a diagnosis that is likely to change their self-perception and the way others interact with them, during their formative years.
- The methodology adopted departs significantly from the NHMRC guidance on national guideline development. We draw attention to the methodological concerns in this response and will provide more detail in a specific response to the Technical Paper and the Evidence Tables under separate correspondences.

¹ (<http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015>) and Medicare data reveal that Paediatricians diagnosed 97% of the 10,000+ children (age 0-12 years) who received a new diagnosis of ASD in 2015-16.
Response to draft guideline for ASD assessment, 19 October 2017



Chapter 3. Overview

We support the need to improve the consistency and accuracy of assessment of neurodevelopmental and behavioural conditions, particularly in relation to the diagnosis of ASD, in Australia.

We are pleased to see that the complexity and variability of clinical presentations that may give rise to concerns about ASD are recognised. As a constructed diagnostic group, rather than a biological diagnosis, many of the signs and symptoms associated with ASD can also be associated with other neurodevelopmental and behavioural conditions that are differential diagnoses to, or co-morbid with, ASD. The diagnosis of ASD requires an assessment of behaviour in the context of environment, involves a subjective element and carries with it a degree of inherent uncertainty. For many individuals, the diagnosis and functional needs may not remain stable over time and this must be considered within the broader guideline development.

For these reasons, we do not support the approach that diagnostic accuracy and consistency can be improved through a specific ASD diagnostic pathway. Such an approach is inconsistent with the principles underpinning the draft guidelines. The diagnostic pathway should remain part of a neurodevelopmental and behavioural assessment process to ensure the diagnostic decision is well informed and that the risks of an incorrect decision are properly considered.

We agree with including a greater emphasis on function and care needs and a focus on both strengths and deficits. Requiring diagnostic certainty for ASD is not an appropriate or equitable criterion for gaining access to support and care services.

Recommendation:

The diagnostic pathway for all children presenting with developmental and behavioural concerns should be through a comprehensive developmental assessment which includes an assessment of both functional and support needs, in order to determine the most appropriate diagnosis, or diagnoses, when sufficient clarity is achieved.

Recommendation:

Criteria for determining access to support services should be based on an assessment of functional needs rather than a specific diagnosis.

3.2 Definition of ASD

The NBPSA support the definition set out.

However, the definition is not consistently applied throughout the document. For example, the assertion in Table 10 that “ASD can be reliably and validly diagnosed at 2 years” does not apply to children who do not develop ASD signs and symptoms until later in their life. ASD covers a broad spectrum of presentations and severity and it is unrealistic to imply that ASD can always be reliably diagnosed (or ruled out) at such an early age.



3.3 Diagnostic criteria for ASD

With ICD-11 due to be released in 2018, the NBPSA believe that these draft guidelines should reference the beta version of ICD-11 in this section and then update the document upon their release.

Recommendation:

Reference to the diagnostic criteria should be to the 'most current versions' of the DSM and ICD diagnostic criteria, rather than specific versions of these documents.

3.4 Scope of the guideline development process

The NBPSA supports the contributions consumers, and professionals outside of the health sector, make in the development of draft guidelines.

However, although the draft guidelines promote the principle of evidence-based research informing diagnostic assessments and clinical decision making, we have identified a number of issues with the methodology set out in the Technical Report and the evidence presented in the Evidence Tables that creates an internal inconsistency between this principle and the recommendations as written.

Recommendation:

That the original NHMRC categories be applied to the evidence tables in the interests of transparency and consistency with the nationally recommended protocol for Guideline Development.

That an independent review be arranged with the NHMRC as soon as possible and prior to further development of the guidelines so that any methodological changes that may be needed can inform future considerations.

We are compiling further analysis for the Technical Report and Evidence Tables and this will be provided separately.

Chapter 4. ASD Assessment Guiding Principles

The NBPSA supports the guiding principles set out.

Recommendation:

The NBPSA recommends consideration of an additional guiding principle: that access to supports and services should be triggered by a formal assessment of function and needs that demonstrates functional impairment, not by a diagnosis of ASD, a syndrome that, by definition, covers a wide range of functioning, ability, disability and support needs.

Our reasoning for making this recommendation is that a number of children whose presentation may be considered as being within the boundaries of the autism spectrum will require very little or no support over that provided by their families and existing community or educational resources. On the other hand, children with significant and urgent needs for support and treatment services may not meet diagnostic criteria for ASD at the time of assessment but may do so later in their development. A child's needs, not the presence of a diagnostic label, must be used to determine eligibility and prioritisation of access to intervention and support services.



The opening sentence in section 4.1 would be better expressed in the following terms: *“This principle is based around the key concept that the primary **sources of** information required during and assessment of ASD are the individuals undergoing assessment and their family and carers.”*

Chapter 5. ASD Assessment Scope

5.1 Content of an ASD assessment

Recommendation:

The NBPSA supports assessment of function and support needs as one component of a broader, comprehensive neurodevelopmental and behavioural assessment that also considers clinical investigations, possible differential diagnoses, co-morbidities and other biopsychosocial influences on behaviour and development.

Functional and needs assessment should occur prior to, or early in, the diagnostic process. The results of the functional and needs assessment should inform the priority and type of early intervention and support services, regardless of whether a diagnosis is able to be made. The results of the baseline assessment and the concept of assessing response to intervention over time can also provide information that is important in the formulation of a valid, reliable diagnosis. Methods used to assess for function must be tailored to the age and capabilities of the child. (An example of the response to intervention concept is provided at the end of our comments on Section 9.3)

5.2 Co-ordination of an ASD assessment

The NBPSA supports the need for a well-coordinated assessment process, with good connections and communication between all professionals involved, particularly for those requiring more complex and comprehensive assessment.

Developmental assessment can be complicated and stressful for children and carers. It is important that the coordination function and the advice and support is clinically informed.

Chapter 6. ASD Assessment Roles

6.2 Referrer

Consumers and education professionals provide essential information for functional and diagnostic assessment but do not have the relevant expertise to refer children directly for clinical assessments as many of the features that might suggest ASD may in fact be attributable to, or co-morbid with, other disorders; alternatively, they may be present for other reasons (e.g. developmental trauma).

Recommendation:

Referral and assessment of children for neurodevelopmental or behavioural concerns, including concerns about ASD, must be carried out within existing health system referral processes, rather than creating unnecessary parallel processes that duplicate existing structures and focus on one diagnosis. Referral for a neurodevelopmental and behavioural assessment must come from a child's primary care provider.

Direct access to primary health care providers is readily available to parents or individuals who are concerned about ASD. Education and health professionals who are not involved in neurodevelopmental care but have concerns can advise families to seek assistance from a primary health care provider.



Without a primary health care professional as the primary referrer, secondary and tertiary services are at great risk of becoming overwhelmed by the additional demand for these services through an increase in self-referrals or referrals from allied health and other staff working in the education sector.

Also, primary health care professionals (e.g. maternal and child health nurses) can assist with access to existing funded services that are relevant, including state funded community child health (staffed by allied health professionals who are child experts) and state and federally funded early intervention services (staffed by allied health professionals and learning experts).

Existing Medicare funding mechanisms for important components of further assessment and access to intervention require involvement of a paediatrician or psychiatrist, following referral from a general practitioner. To make recommendations that do not enable access to existing services and funding will potentially deprive families of assessments and interventions, unless another funding stream for these actions is identified.

6.3 Coordinator

The NBPSA supports the provision of well-coordinated care.

The coordination function should remain the responsibility of the lead clinician. This does not prevent a clinician choosing to delegate some coordination activities to an administrative resource or the use of technology to provide practical assistance and information.

6.4 Diagnostician

The NBPSA does not support broadening the professional groups who can act as primary diagnosticians under the current accreditation and training arrangements. Doing so will increase, rather than reduce, the range and variability in ASD diagnosis nationally and increase the risks to groups such as children and young people, especially pre-schoolers and those who do not communicate.

The level of evidence presented is insufficient to support broadening current arrangements, particularly recommendations supported by CB2 and CB3 ratings.

The roles and responsibilities of a diagnostician are not adequately described or explained. For example, the professional responsibilities (including adequate professional indemnity cover) associated with a diagnosis made by a single clinician are considerable. Requirements include a detailed knowledge of normal and abnormal development, a wide range of other neurodevelopmental and behavioural conditions, including genetic disorders, as well as other mental health and physical considerations and the ability to assess family environmental factors.

There are considerable risks in both making and excluding an ASD diagnosis. For the child, risks include over and under-diagnosis with potential for missed causes and comorbidities and subsequent incorrect treatment and management planning. Children, in particular, may be significantly disadvantaged or put at risk by an inaccurate diagnostic decision. For the family, risks include wrong information about their child or young person's problems, the likely causes and how to best decide on appropriate interventions. For the community, risk include misallocation of resources for assessments and intervention.

Recommendation:

A diagnostician with the capacity to diagnose without the support of a multidisciplinary team must be a suitably credentialed medical practitioner with relevant advanced training in the field of developmental-behavioural paediatrics. We strongly recommend that for preschool or young people who are not communicating, a paediatrician with relevant advanced training in the field of developmental-behavioural paediatrics should be the only suitable diagnostician.



All diagnosticians without the support of a multidisciplinary team must have:

- broad biopsychosocial assessment capacity;
- extensive clinical training and experience across the range of disorders of development, learning, behaviour and mood;
- extensive experience in the assessment and clinical care of children with these concerns across the age range; and,
- specific skills and expertise in ASD.

These specific skills and expertise in ASD must be regulated and a suitable credentialing process needs to be established and monitored. An algorithm for the development of this process should be able to be developed but the current draft guidelines do not provide sufficient details to allow for this.

The draft guidelines exclude a sizeable group of highly skilled and experienced Senior Career Medical Officers (SCMOs) and Senior Child Health Medical Officers who are working in the public sector as key diagnosticians within multidisciplinary teams.

Recommendation:

The NBPSA strongly recommends that the relevant professional colleges and associations must be consulted on the roles, responsibilities, qualifications, experience and training appropriate to their discipline in relation to both Tier 1 and Tier 2 roles and responsibilities as diagnosticians and informants.

Existing international guidelines do not attempt a process of evidence evaluation for ascribing diagnostician roles. Roles are assigned on the basis of legislation or the training and skills required to perform a role.

6.6 Professional informants

Recommendation:

Social workers and registered nurses would be valuable additions to the list of proposed professional informants.



Chapter 7. ASD Assessment Settings

We support the principle of direct observation of the patient: in the clinical setting, by the diagnostician, and in a community setting, by a professional informant with allied health qualifications and appropriate experience and accreditation in neurodevelopmental and behavioural assessment. In regional and remote areas, however, distance and workforce limitations may render such a requirement impractical or impossible to implement.

The use of telehealth in these circumstances requires further consideration. The risks from over and under diagnosis outlined in Section 6.4 must be considered and elevated when the diagnostician does not have face-to-face access to the person being assessed.

Health services, disability service providers and education all face similar challenges in delivering services in remote and hard to reach communities.

Recommendation:

Specific guidance should be developed for the use of telehealth in neurodevelopmental and behavioural assessments that includes: managing the expectation for clinical diagnosis when adequate clinical observations are not available, support for local clinicians and focusing on functional and support needs assessment and access to appropriate services.

That, as a part of introducing any new national guidelines, additional work be undertaken across the health, disability and education sectors to develop specific considerations for rural and remote implementation, including sharing of communications, training and support intrastate.

Chapter 8. Initiating an ASD Assessment

Recommendation:

Referral for a neurodevelopmental and behavioural assessment and consideration of a possible ASD diagnosis must come from a consumer's primary care provider.

Without a primary care provider as the primary referrer, secondary and tertiary services may be overwhelmed by the additional demand for these services through an increase in self-referrals or referrals from allied health professionals who do not work in neurodevelopment and employees working in the education sector. Under current Medicare arrangements, a referral is required to trigger the MBS payment system for specialist consultations.

8.1 Recognition of signs and symptoms of ASD

The factors listed in Table 5 only slightly increase the risk of ASD at most. If all children displaying these symptoms were referred for an ASD assessment, the waiting lists would significantly increase and a lot of anxiety, particularly for parents and their children, would be created unnecessarily.

Recommendation:

That Table 5 be omitted and that the clinical expertise and judgement of the primary care provider determines the need for a referral.



8.2 Making a referral for an ASD Assessment

The title of this section is misleading as it presumes that diagnosis of ASD is the only possible conclusion for a child who has been referred for a comprehensive neurodevelopmental and behavioural assessment.

Recommendation:

That the terminology used in this title and throughout the draft guideline be changed to more accurately reflect the assessment process. For example, “making a referral for a complex developmental assessment” would provide a more accurate description of the process that is undertaken.

Chapter 9. Diagnostic Evaluation

9.1 Purpose

The neurodevelopmental and behavioural assessment can be a long process because of significant variance in clinical presentations and reasons for initiating the referral.

The NBPSA recommends that the draft guidelines clearly describe the potential risks of diagnosis, the risks associated with misdiagnosis, the risk of missing other diagnoses, and the risks from over diagnosis. For example, the risk of missing an associated Intellectual Disability or diagnosis of Fragile X syndrome goes beyond the child, extending to future pregnancy decisions for the family, including female siblings.

In some circumstances, individuals and their families may not want, or choose not to associate with, a diagnostic label of ASD. This will impact the services they choose on the path to understanding their strengths, difficulties and needs.

Recommendation:

When individuals display needs that require intervention, or have functional deficits, and choose not to identify as having been diagnosed with ASD, these families or individuals should not be disadvantaged, through denial or reduction in service, by this choice. The draft guidelines must provide clarification of this to support clinicians and families in these circumstances.

9.2 Diagnostic evaluation

We welcome the inclusion of the beta ICD-11 diagnostic criteria into these draft guidelines. As the ICD-11 criteria have been stated by the authors to have a “strong focus on assessing functional impairment”, we believe that this should be further iterated in Table 6.

9.3 Diagnostic Evaluation Structure

While we are familiar with tiered approaches to health and disability care, the evidence presented in the Evidence Tables on this matter is not sufficient to support this approach for ASD diagnosis. The concept of a two-tier approach to diagnosis requires further consideration.

The NBPSA supports a staged and progressive approach to neurodevelopmental and behavioural assessment, based on individual need and complexity.



However, any approach must be structured to ensure known risk factors for an inaccurate diagnosis are excluded and that appropriate care is taken for those in vulnerable circumstances or where an incorrect decision may have substantial adverse consequences in later life.

Recommendation:

That further expert consultation be undertaken on the utility of a tiered assessment approach within existing care delivery models, including consideration of primary, secondary and tertiary care delivery components.

Figure 4 represents only a small portion of the journey that many individuals will take when pursuing a diagnostic evaluation for neurodevelopmental and behavioural conditions, including ASD. Many children who are referred for a Tier 2 assessment will not have an ASD diagnosis, even after assessments have been completed by the multi-disciplinary team.

Recommendation:

That Figure 4., and associated narrative, be extended to include ongoing diagnostic uncertainty, and also to illustrate the link to access to early intervention services. The function and needs of the child should be the primary consideration when determining referral to additional support and services, including early intervention.

A link to re-evaluation of the patient after an initial diagnosis should also be included into the flowchart. If functional and needs assessment is completed early, as described above, there are many potential positive flow-on effects for the child and family, and for streamlining the diagnostic process.

For example, if a child aged 3 presents with little connection with peers, limited communication, has a preference for routines and does not like loud noises and, following a functional and needs assessment, is found to have sufficient difficulties to warrant referral to an early intervention service.

That service would develop a program to cater to the child's learning, functional and support needs and appropriate strategies to improve communication. If the early intervention providers do not see a response to their interventions and identify a severity and breadth of difficulties that warrant further neurodevelopmental and physical assessment, they will refer to a paediatrician. The paediatrician will then have important information about the strengths, difficulties and needs of the child and family at the time they are seen, as well as information about whether there has been a response to intervention. This will assist a timely decision about whether further investigation and assessment, beyond the ongoing monitoring provided during early intervention, is needed or not. If further assessment is needed, a professional informant has been established, some relevant information is already available and can guide the most efficient assessment pathway.



9.4 Tier 1 diagnosis

Recommendation:

That only a medical professional with expertise in the diagnosis of ASD and other neurodevelopmental conditions should be performing in the role of a single diagnostician. (See also our comments at Section 6.4)

The diagnostic process should not consider ASD alone, but the wide range of differential diagnoses and co-occurring conditions to minimise the likelihood of misdiagnosis or over diagnosis. The diagnostician should work with a professional informant, from a different professional discipline or specialty, also having input into the process. The exact role of that person should not be so prescribed as to create unnecessary barriers to pursuing a diagnosis, particularly for families in rural and remote areas.

The NBPSA strongly supports the concept of monitoring response to intervention, as outlined in the example above at the end of Section 9.3. This is not considered in the current diagnostic outcomes provided within the document.

Recommendation:

That the draft guideline is updated to reflect the inclusion of response to early intervention, regardless of the diagnostic outcome. For example, a young child who meets ASD criteria may be re-assessed after a period of appropriate and targeted intervention to determine future support requirements.

The current diagnosis categories, set out in Figure 5, will be redundant when ICD-11 is released and should be updated accordingly.

9.5 Tier 2 diagnosis

Many people who enter the diagnostic pathway for a neurodevelopmental condition, including exploration of the likelihood of ASD, are likely to be part of a multidisciplinary assessment process. We agree with the draft guidelines stance that “[if] consensus on a diagnostic decision was not achieved among the diagnosticians following an extensive Tier 2 diagnostic evaluation, the diagnostic decision should be deferred until re-assessment after a specified period of time.” When this situation arises, the necessary supports, in line with assessed functional needs, must still be provided.

Tier 2 diagnostic processes set out in the draft guidelines, however, provide three narrow diagnostic outcomes for individuals completing the assessment that do not accurately represent clinical reality.

Recommendations:

That the potential diagnostic outcomes should be broadened, in line with our recommendation in 9.4, to include the diagnosis, or further evaluation, of other neurodevelopmental disorders.

That assessment includes direct observation of the individual in two or more settings, where at least one is a community setting. However, while the diagnostician should make the observation in the clinical setting, an allied health professional with relevant skills in ASD assessment would usually be better placed to complete these observations in the community setting.



Families and education staff often do not have specialist-level training in broad developmental norms and disorders in children. Observations from skilled allied health professionals are essential and reduce over-reporting and over-interpreting of behavioural problems as ASD symptoms. If the diagnostician were to complete these observations, the duration, expense and waiting lists for assessment would significantly increase and this provides no benefit to the child or the wider health and disability system.

Alternative pathways must be developed for patients living in rural and remote location to ensure these patients and their families are not disadvantaged by their geographic location and limited access to clinicians with the required skills and expertise. (See also the comments at Section 7. Assessment Settings)

Information from early intervention services will provide valuable information for the multidisciplinary assessment through multiple engagements with skilled observers in a child's usual settings.

The draft guidelines fail to mention other key parts of diagnostic assessment including targeted physical examination and the appropriate investigations (such as genetic testing) required to detect co-existing and/or differential diagnoses.

9.5.3 Information Collection – Standardised ASD Diagnostic Tool

There is insufficient evidence upon which to base a recommendation that an ASD specific diagnostic tool be included as part of an assessment for children and young people presenting with neurodevelopmental differences of the types seen in ASD. There does not seem to be consistency at level 1 when reading the extracts provided in evidence table 47 from draft guidelines, the Delphi or the scientific committee to include the current wording of this recommendation.

Recommendation:

The decision about whether an ASD specific diagnostic tool is used should be left to the discretion of the diagnostician until there is a higher level of evidence to support inclusion, or strong consensus that this would add value to all assessments.

Chapter 10. Functional and Support Needs

The NBPSA strongly supports the value and necessity of the functional and support needs assessment.

Recommendation:

That the functional and support needs assessment be completed prior to, or concurrently with, the diagnostic assessment process. The outcome of the functional and support needs assessment should be used to determine, or assist in the determination of:

- whether pursuit of a diagnostic assessment is necessary or warranted; and,
- the patient's access to support through the NDIS including access to early intervention services.



10.2 Functional and support needs assessment structure

Recommendation:

Given the NBPSA recommendations on diagnostic assessment, the professional qualifications skills, training and experience required for functional and support needs assessment will need to be more clearly described.

While some elements of this assessment can be carried out by paediatricians, the allied health professions and others have access to a greater array of tools and practical opportunities for undertaking functional and support needs assessment.

There is additional complexity in assessing function in pre-schoolers and those who are unable to communicate. The NBPSA would welcome the opportunity to contribute to development of recommendations for assessment in these two groups.

10.3 Functional assessment and 10.4 Support needs assessment

The use of standardised assessment tools is supported, with the caveat that a more detailed review will be needed to decide appropriateness and validity in pre-schoolers and individuals who do not communicate.

10.5 Repeated assessment

We agree that “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.”

Recommendation:

As stated in previous sections, funding should be based on the needs of the child, in accordance with the guiding principle of individual and family-centred care. A child who does not receive a diagnosis of ASD or any other neurodevelopmental condition should be provided with the required support as established through the completion of the functional and support needs assessment. A child with an ASD diagnosis should have interventions and services tailored to their needs.

Chapter 11. Sharing ASD Assessment Findings

Recommendation:

A comprehensive formulation should be developed, including details and outcomes of the diagnostic process and the results of the functional and support needs assessment. This can then be used for multiple purposes, including development of a child and family centred management plan and determination of the level of support.



Chapter 12. Important Considerations

12.1 Age

The statement in Table 10, may be misinterpreted and fails to account for the complex and often prolonged process to pursuing a diagnosis of ASD:

“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.”

In its present form, we have concerns with this statement.

Recommendation:

The commentary in chapter 3, section 2 is much clearer and should be replicated in this section to prevent any misinterpretation.

Specific consideration should be given to the assessment of function and needs for preschool children and individuals who do not communicate. This is because:

1. all facets of ability, symptoms and function are being assessed using behaviour; and,
2. preschool children and individuals who do not communicate are more reliant on their parents or carers to function.

As such, specific consideration of how to assess function and needs is warranted in these two groups. The NBPSA would like to contribute to the formulation of appropriate assessment for these two groups.

Medical professionals with additional training in the assessment, diagnosis and treatment of conditions present in the adolescent and young adult (AYA) population can diagnose patients to the age of 25 years. The draft guidelines should reflect this.

12.4 CALD backgrounds

We strongly support the statement that “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.”

12.6 Differential diagnosis and co-occurring conditions

The inclusion of Table 14 provides no assistance to a clinician who is supporting a patient through the assessment and diagnostic pathway for a neurodevelopmental condition, with little rationale being provided for the inclusion of some conditions and exclusion of others.

Recommendation:

That Tables 14 and 15 in this section are reconfigured to describe the differential diagnoses and co-occurring phenotypes, as per the current contents of Table 15, and the most common aetiologies only.