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Neurodevelopmental and Behavioural Paediatric Society of Australasia

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

18 March 2018

Dear Andrew,

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

NBPSA would like to acknowledge the collaborative approach of the Research Executive Team and the significant development of the guideline through this process. We are pleased to continue our support for improving consistency and accuracy in the diagnostic and functional needs assessment of neurodevelopmental and behavioural conditions, including Autism Spectrum Disorder.

The clearer focus on the assessment of functional needs is most welcome. The functional needs of a child must be the primary determining factor for gaining access to care and support services. For complex neurodevelopmental conditions that present with a broad range of needs, abilities and disabilities, diagnosis should not be the sole determinant of need, nor the sole criteria for access to care and support.

We recommend further changes to the revised guideline to reflect best practice, and to maintain consistency and standardisation in ensuring assessments of concerns about ASD are not undertaken in isolation from the consideration of other conditions that may be associated with, or be the cause of, these concerns. We suggest this in the context of our previous concerns over a proliferation of ASD specific assessment services and related resource implications. After a review of the technical report in the time available to us, we also raise questions to clarify the methodological review processes.

We note that publication of guidelines alone will not address the broad range of assessment approaches amongst clinicians nor facilitate consistent implementation across the range of jurisdictional and practice settings. We will be recommending that implementation planning include developing descriptions of the competencies required for each professional group involved in neurodevelopmental and behavioural assessments. This work should be undertaken collaboratively with the relevant professional bodies and should precede implementation of the guidelines. Competency descriptions will inform future training requirements and help in developing a shared and standardised language that will, ultimately, help families, clinicians, disability support planners and providers, and educators, when establishing care plans and evaluating their effectiveness.

We would be pleased to continue to work with the CRC through the remaining stages of the guideline development.

Yours sincerely,

Associate Professor Gehan Roberts
President

Neurodevelopmental and Behavioural Paediatric Society of Australasia (NBPSA)



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

Introduction & Summary

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 welcome many of the changes to the revised guideline and continue to 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 increased emphasis on the need to assess ASD concerns within the context of neurodevelopmental and behavioural assessment pathways. We do ask however, for further changes within the guideline to maintain this intent and improve consistency in language and structure throughout the document.

We are concerned that publication of guidelines alone will not address the broad range of approaches across clinicians involved in the assessment and management of possible ASD concerns. Further work is required outside the Guideline to facilitate consistent implementation across the range of jurisdictional and practice settings.

We recommend that further work be undertaken to develop descriptions of the competencies required for each professional group involved in neurodevelopmental and behavioural assessment of ASD concerns. This work could be undertaken collaboratively with the relevant professional bodies and should precede implementation of the guidelines. Such an undertaking would also help in developing a shared and standardised language that will ultimately help families, clinicians, disability support planners and providers, as well as educators, to maintain effective lines of communication when establishing care plans and evaluating their effectiveness.

While these Guidelines are a good start, their effectiveness will depend on how they are used by clinicians and planners at the point of complex developmental and functional assessment.

Perhaps the most significant risk to the guidelines achieving their intended purpose, is the ongoing use of the ASD diagnosis as a criterion for eligibility for funding and support across health, education and disability services. The functional needs of a child should be the primary determining factor for gaining access to care and support services. For complex developmental conditions that present with a broad range of needs, abilities and disabilities, such as ASD, diagnosis should not be the sole determinant of need, nor the sole criteria for access to care and support.

Accordingly, we also recommend that further cross-disciplinary and cross-sector work be undertaken to develop a consistent approach to the assessment of functional needs for children.

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.



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Detailed comments

Please note that these comments are presented in the order of the guideline structure. Where headings are reproduced for reference purposes, they include amendments in line with NBPSA recommendations. We have not however, highlighted all the amendments that will be required through the document to ensure consistency.

Consistency in using the term ‘neurodevelopmental assessments’, rather than ‘ASD assessments’

While much of the introductory text describing the process and context of neurodevelopmental and behavioural assessment of ASD concerns has improved significantly, later parts of the document still use terminology such as “ASD Assessment Team” and “ASD Assessment”. For many sections of the guideline, this terminology:

- implies that an “ASD Assessment” is a standalone process, as opposed to a component of a bigger picture; and,
- promotes the notion that diagnosis is a “case-finding” exercise for something that is clearly present or clearly absent.

We recommend that references to “...ASD Assessment...” throughout the document be changed to either “...neurodevelopmental and behavioural assessment...” or “...assessment of ASD concerns...” as appropriate to the context. Reference to “...ASD Assessment Team...” should be replaced with “...clinicians involved with neurodevelopmental and behavioural assessment...” or “...clinicians involved in the assessment of ASD concerns...” or similar, within the entire document.

Section 3.1 Purpose

The term “frank presentation” and the identification of “obvious” clinical features in a patient presenting with a possible neurodevelopmental concern is highly subjective. We recommend that further guidance is provided to justify what is meant by these phrases through the inclusion of case examples.

Section 3.4 Scope of the Guideline

We recommend that the opening paragraph in this section is amended as follows:

~~“Where possible, †This Guideline is intended to operate within the describes an assessment processes that is applicable for individuals presenting with signs or symptoms of a broad range of neurodevelopmental conditions. However, †To meet the defined objectives of the project, this Guideline retains a focus on applying this~~ focuses on aspects of the neurodevelopmental and behavioural assessment processes relevant to process to the context of individuals presenting with concerns about possible ASD signs or symptoms. It is essential that the assessment of concerns about ASD is not undertaken in isolation from the consideration of other conditions that may be associated with or be the cause of the concerns being raised”

It is most important that the broad range of co-morbid and/or differential diagnoses are considered when pursuing a neurodevelopmental assessment in any clinical setting.



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Section 3.6 Instructions for Using this Guideline

We recommend that the opening paragraph in this section is amended as follows:

*The Guideline represents a 'minimum national standard' for the assessment of children, adolescents and adults ~~where~~ **for a diagnosis of ASD is a possibility.***

We have concerns about the guideline's utility in this current form, due to its size and complexity. We recommend that further work is completed during implementation planning to clarify application across various practice settings, highlight professional roles and responsibilities, and we recommend that practical aids be developed, such as additional flowcharts. The reality of a busy, clinical setting is that clinicians will look almost exclusively to the flowchart summarising a clinical guideline in order to inform their practice.

While we agree that *"Clinicians are responsible for ensuring they achieve and maintain requisite professional training and expertise ..."*, the current variability in approaches to considering possible ASD diagnosis suggests that more is needed.

Professional specific competencies will be required to ensure the guidelines are implemented as intended. This is the role of relevant professional and training organisations.

To assist in improving variability in practice on within our own profession, NBPSA has contributed to RACP training development (using the framework of 'Entrustable Professional Activities') and is also developing descriptions of the core paediatrician competencies in neurodevelopmental and behavioural practice, including those applicable to assessments. We would be pleased to collaborate with other professional groups identified in these guidelines and support the development of companion competency statements for the disciplines typically involved in neurodevelopmental and behavioural assessments.

We recommend that implementation planning include collaborative work to develop descriptions of professional competencies for each professional group identified guidelines.

In the final paragraph on page 15 of the revised document, "CBR - 1" is described as the *"the highest possible rating"*. Given the paucity of evidence acknowledged in the Technical Paper, and consensus nature of the supporting evidence gathered, we suggest *"the best information currently available"*, or similar would be a more accurate statement.

Section 4.6 Lifespan Perspective

We suggest the following amendment to the first sentences:

*"This principle is based around the key concept that ASD **and many other neurodevelopmental disorders are** ~~is~~ most often ~~a~~ lifelong ~~diagnosis~~ **diagnoses**, with long- term implications for the individual and their family."*



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Section 5.1 Content of an **assessment for ASD concerns** **Assessment**

As previously discussed in Section 3, we recommend this heading be changed, as noted above, along with the following amendments to the text:

Paragraph 1.

~~In its most literal form~~ *For many medical concerns, a diagnostic evaluation seeks to determine whether an individual meets defined criteria for a given health or medical condition. However, for ASD, it is critical for the future service delivery to the individual being assessed to not just understand the presence or absence of clinical diagnoses, but also evaluate the functioning and support needs of the individual and their care givers."*

Paragraph 3.

The Diagnostic Evaluation seeks to answer the questions: "Does the individual meet criteria for a clinical diagnosis, such as ASD and other differential or comorbid conditions?" and "If the individual does not meet criteria for a clinical diagnosis, are there other considerations diagnosis that explains the presentation?"

This language used in Section 10.4 (page 46) of the document more accurately represents this statement.

Paragraph 4

The Guideline recommends ~~two sequential~~ 'stages' for Diagnostic Evaluation. The Diagnostic Evaluation process will usually commence with a Single Clinician Diagnostic Evaluation (Stage 2), which is a simplified assessment to determine whether an ASD or another diagnosis can be confirmed or ruled out with certainty. If diagnostic certainty cannot be achieved by the single clinician, the individual progresses to a Consensus Team Diagnostic Evaluation (Stage 3) for more detailed assessment, involving additional clinicians and investigations in the domains of diagnostic uncertainty.

Although these stages are presented sequentially, they may occur concurrently and some children, if complex, may start at stage 3.

Section 5.1 Content of an **ASD** assessment

The NBPSA welcome the inclusion of examples to consolidate understanding of the staged approach to assessment and potential diagnosis of a neurodevelopmental condition.

However, in Figure 3, Example 2, we are unsure which GPs are to undertake a medical evaluation in the context of a neurodevelopmental and behavioural assessment. We suggest that this scenario is linked to the development of GP competencies and the training referenced in the RACGP submission to the first consultation round.

Furthermore, the recommendation in this example for "re-assessment in 6 months" is unfounded. The optimum time for reconsideration depends on age and stage of development. It will, in some circumstances, be better to wait for significant change in function or presentation, or for new information to become available (e.g. response to intervention, supports or results of an additional assessment), before reassessing; for many children this may occur over 1 to 2 years. We also suggest that this review may best be undertaken as a Stage 2, rather than Stage 3 review.



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Section 6.3 Clinicians involved in an ASD Assessment Team

The language in much of this section is inconsistent with the concept of the single clinician diagnostic evaluation. We suggest the first sentence is replaced with:

“The clinicians typically involved in assessing ASD concerns are listed in Tables 4 and 5.”

The three CBR -X recommendations should be amended to replace “... members of the ASD Assessment Team...” with “... clinicians involved in assessment of ASD concerns...”

Table 4. Recommended professional disciplines eligible to undertake assessment of ASD concerns assessments

We recommend that further work be undertaken, prior to guideline implementation, to develop descriptions of the requisite discipline specific competencies required by the professional groups listed as eligible to undertake neurodevelopmental and behavioural assessment of ASD concerns. This work should be conducted collaboratively by the relevant professional bodies.

NBPSA is currently developing descriptions of the competencies for neurodevelopmental and behavioural paediatricians, including assessments. We would be pleased to collaborate with the other professional groups to share this work and to build cross discipline understanding of skills and contributions each brings to the assessment process.

We see this work as being an essential pre-requisite to the implementation of the guidelines.

Table 5. Expertise, training and membership from clinicians commonly involved in the ASD assessment team. Please note that the Guideline recommends that medical practitioners with other selected qualifications and expertise can take part in ASD assessments (See Sections 9.4, 10.1, 11.1)

The NBPSA do not believe that all paediatricians will have the necessary skills and qualifications to conduct neurodevelopmental assessments. We suggest that the ‘paediatrician’ section of the table is amended to:

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~~ at least one of the following paediatric specialties - Community Child Health, General Paediatrics, or Paediatric Neurology - through the Royal Australian College of Physicians. These Advanced Training programs include specific training in neurodevelopmental-behavioural assessment in a Multidisciplinary Framework which are requisite skills of a paediatrician performing neurodevelopmental assessments in the clinical setting.

Section 8 Initiating referral for an assessment of ASD concerns Assessment

The NBPSA do not support the notion that parents can diagnose neurodevelopmental conditions in their children, as may be implied by the statement: “.....evidence that parents have moderate to high levels of accuracy in identifying clinically – relevant developmental matters”. However, we acknowledge that parents and carers have considerable insight into the function, needs, strengths and deficits of their children and suggest the following statement takes this into consideration, whilst ensuring that the clinician is ultimately responsible for completing the required assessments that may lead to a diagnosis:

“Whilst levels of parental concern are not reliable indicators of specific diagnoses (e.g. ASD), there is evidence that parents have moderate-to-high levels of accuracy in identifying clinically relevant developmental concerns that warrant further assessment.”



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Section 8.1 Professionals Involvement

We suggest the following amendment to the second CBR-X in this section:

It is suggested that the primary health care provider has received formal professional training in typical child development and the signs and/or symptoms of common neurodevelopmental and behavioural conditions, including those associated with ASD, as well as common co-occurring and differential diagnosis conditions.

Section 9 ~~Stage 1~~ Comprehensive Needs Assessment

For many patients, the completion of functional assessment activities will overlap & intersect with diagnostic assessment activities. For ease of disposition, elements of functional and diagnostic assessments may need to be described separately in the guideline. It is important to be clear however, that they are not necessarily intended to be conducted as consecutive or distinct steps. To do so would increase the cost and practical burden of many assessments and may serve to artificially limit the range and depth of information able to be gathered.

Comprehensive function and care needs assessment should be made in the context of a clear understanding of the individual's developmental or cognitive stage and social and family context. Much of the information gathered will be applied to the evaluation of both functional need and diagnostic outcomes. Accordingly, it is important to make it clear that functional and diagnostic assessment activities are not necessarily intended to be conducted as consecutive or distinct steps.

We ask that this point be made clear throughout the guideline, particularly in those sections that focus on one or other aspect of the assessment.

Section 9.2 Assessment of Function: Information Collection

We suggest the following amendment to the second CBR-X in this section:

"It is recommended that information is collected during an Assessment of Functioning on the following topics:

- Medical and health history;*
- Family **functioning and family** history;*
- ..."*

NBPSA supports the use of standardised assessment tools for the assessment of neurodevelopmental conditions but believe that the use of such instruments is dependent on context. As such, we do not see these as an 'essential' element of all neurodevelopmental assessment. A comprehensive neurodevelopmental tool that includes the assessment of function and that is completed by a skilled clinician, or several clinicians within a multidisciplinary team, can be as effective, if not more so, than a prescribed standardised test.

As such, we recommend that the professional judgement and clinical expertise of the diagnostician should be used to determine the most effective assessment tool and that the patient and clinical context is a primary consideration when selecting the best way to proceed.

This will, when coupled with a structure descriptions the professional competencies underpinning each of the professional contributions involved in neurodevelopmental and behavioural assessments, support a more robust and flexible framework for clinicians.



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Page 37.

We recommend the following amendment to the narrative paragraph:

*“Standardised assessments of development, **social, communication, behavioural** and/or cognitive abilities may assist the comprehensive needs assessment for children (Web resources). These assessments are important in facilitating a comparison of an individual’s ability in relation to age-appropriate developmental and/or cognitive skills, as well as benchmarking performance for future follow-up assessments. ~~These assessments may be less applicable for adolescents or adults who present for an assessment, but can also provide helpful information to determine level of functioning.~~”*

The broad generalisation of the last sentence is not helpful and may be misunderstood. For example, whether or not a reliable assessment of cognitive abilities (e.g. in very young or non-verbal children) is available may be of greater significance in considering whether further standardised testing is indicated.

Page 39.

We recommend that an additional dot point needs to be added to the list of support needs:

- Focus on enhancing and utilising strengths to provide a formal opportunity for learning and development.

Section 9.3 Assessment of Function: Settings

As noted above, please make it clear that clear that functional and diagnostic assessment activities are not necessarily intended to be conducted as consecutive or distinct steps.

Section 9.4 Medical Evaluation: Professionals Involvement

Page 40.

This section should be presented by referring to medical screening initially, with further medical investigation to be undertaken in line with the assessment and diagnostic findings.

First CBR - X

*“It is recommended that a Medical Evaluation **and investigations relevant to neurodevelopmental and behavioural disorders are** is conducted by a medical practitioner who holds general or specialist registration with the Medical Board of Australia **and has demonstrated competencies in collecting, synthesising and acting on the areas set out in Section 9.5.** [Evidence Table 35]”*

9.5 Medical Evaluation: Information Collection

We recommend the following amendments:

*It is recommended that the following information is collected and **synthesised** during a Medical Evaluation:*

- *Medical and health history;*
- *Family history **and Family functioning;***
- *Developmental and educational history;*
- ***Neurodevelopmental and behavioural** ~~ASD-specific~~ symptoms, **including specific ASD concerns;***
- *Other relevant behaviours and/or symptoms;*
- ***Relevant biological investigations for aetiology and comorbid conditions (note further testing may be indicated after diagnostic evaluation (e.g. Chromosome Microarray and Fragile X)***



- *Developmental and growth status;*
 - *Congenital abnormalities and **dysmorphic features**; and*
 - *Neurological, general systems, skin, injury, vision and hearing status.*
- [Evidence Table 38]

Section 10. Stage 2 – Single Clinician Diagnostic Evaluation

Page 43.

Please see comments in relation to “frank presentations” at item 3.1 above.

Section 10.1 Professional Involvement

NBPSA supports the concept of medical practitioners undertaking diagnostic evaluations needing to have relevant experience, training or supervision in the assessment of neurodevelopmental *and behavioural* disorders.

NBPSA is developing work to describe competencies required of paediatricians in neurodevelopmental and behavioural paediatric practice, include those relevant to assessments.

All clinicians involved in making a diagnostic evaluation need to be able to elicit and formulate critical information across each of the biological, developmental/ psychological and environmental domains.

Simply issuing new guidelines to a professional workforce with a wide range of qualifications and experience will not address the wide range of assessment outcomes currently causing concern.

Please refer to the recommendation about professional competencies in our general comments above.

Section 10.2 Information Collection.

Page 44.

We recommend the following amendments to this section:

*Family history **and family function**: Presence of medical, psychiatric, and neurodevelopmental disorders (including ASD) among ~~nuclear or~~ **immediate and** extended family members, as well as relevant social and environment factors (e.g. family violence, substance abuse, neglect, trauma);*

Page 45.

We recommend an amendment to the CBR-X recommendation at the bottom of the page:

~~“It is recommended that the use of ASD-specific assessments may provide considerable assistance in the direct observation of ASD symptoms, but it is recommended that these instruments should not be used as a substitute for the use of clinical judgment, nor as the sole investigation on which an ASD diagnosis is based. in diagnostic decision making, and t~~ Their use in an ASD assessment is at the discretion of the Consensus Diagnosis Team.

[Evidence Table 51]”

Section 10.4 Decision Making and Outcome

In addition to the three outcome options listed, a minimum outcome expectation should be a clear formulation of the individual’s strengths and difficulties, along with an analysis of diagnoses and differential diagnoses, with a summary statement as to whether or not the individual meets ASD criteria.



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Section 11.1 Professional Involvement

As noted above, NBPSA supports the need for minimum requirements for medical practitioners in this role and we are developing statements to more clearly describe the competencies required of neurodevelopmental and behavioural paediatricians.

We suggest that a recommendation be included to the effect that the relevant professional bodies also develop descriptions of competencies for each professional discipline typically involved in a consensus team.

The CBR – X at the bottom of page 48 to be amended to reflect the multiple clinicians involved in the assessment process.

It is recommended that the Consensus Diagnosis Team involves input from at least one other professional, with at least one professional from a different discipline or specialty to the clinicians involved at Stage 2. [Evidence Table 59]

Section 11.4 Decision Making and Outcome

In addition to three outcome options listed, a minimum outcome expectation should be a clear formulation of the individual's strengths and difficulties, along with an analysis of diagnoses and differential diagnoses, with a summary statement as to whether or not the individual meets ASD criteria.

"In some Australian states, tertiary services are available for the assessment of individuals with complex neurodevelopmental disorders. ~~If these services, where available, then it is recommended that~~ can also fulfil the role of the Consensus Diagnostic Team. ~~clients are referred to these services if a consensus decision cannot be achieved at Stage~~

Section 12.2 Content of Communication

In the CBR – X recommendation, the first dot point should include, as a minimum, a clear formulation of the individual's strengths and difficulties, along with an analysis of diagnoses and differential diagnoses, with a summary statement as to whether or not the individual meets ASD criteria. The NBPSA have previously noted this change.

Section 13.5 Regional or Remote Location

We recommend amendments to the CBR – X in this section as follows:

*It is recommended that in circumstances where a clinician with the prerequisite professional background and ASD **neurodevelopmental and behavioural assessment** specific expertise to be a member of a Consensus Diagnosis Team is not present in the local community, a partnership between local clinicians and an assessment team with ASD **neurodevelopmental and behavioural** expertise in another location be facilitated through telehealth or other methods. [Evidence Table 81]*

Section 13.6 Differential Diagnosis and Co-occurring Conditions

We recommend amendments to the second CBR – X in this section as follows:

*It is recommended that members of the **team assessing ASD concerns** ~~assessment team~~ be highly familiar with the full range of potential differential diagnoses for ASD. ~~If a particular~~ **Clinicians without** ~~does not have the clinical qualifications or expertise to adequately evaluate a potential differential diagnosis~~es for a given individual, **should not undertake the assessment of ASD***



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concerns then it is suggested that the individual be referred to a clinician who does have this expertise. [Evidence Table 84]

Table 13 Examples of differential diagnosis and co-occurring conditions

The concerns NBPSA raised previously (Feedback ID 716) have not been addressed.

The combined Table 13 offers no assistance to a clinician supporting a patient through the assessment and diagnostic pathway for a neurodevelopmental condition.

We question the evidence base for including contested concepts such as Auditory Processing Disorder, Sensory Processing Disorder and Pathological Demand Avoidance. Ehlers Danlos Syndrome appears to have been included on the basis of public feedback alone, without scientific justification of its relevance to ASD. We note also that relatively rare syndromes such as Lesch-Nyhan Syndrome are included while a myriad of other equally rare, or more common, aetiologies are excluded. Such a list can only add confusion to an already complex assessment and diagnostic pathway.

We do not agree that evidence-based guidelines for clinical diagnosis should reference conditions solely on the basis that respondents to public consultation found the information “helpful”.

A rational evidence-based threshold should be established to ensure only the most common or likely differential or co-morbid aetiologies are presented. **If not, we recommend Table 13 be removed.** For example, in the paediatric context, common differential diagnoses for a child with social communication and behavioural differences will usually include a hearing loss, specific language impairment, global developmental delay or intellectual disability, a mood disorder or exposure to trauma or other psychosocial stress. In the absence of additional abnormal features on history or examination, other conditions are extremely unlikely.

Section 14.5 Accreditation and Regulation programs

The NBPSA support this statement but have questions and concerns about the changes that have been made to the evidence tables. We request to see the new Evidence Tables prior to confirming our position on this point.

We also recommend that the collaborative work to develop descriptions of professional competencies described above, be undertaken before individual training bodies start this work.

Section 14.7 Guideline Development

The NBPSA do not support the development of separate guidelines for diagnostic assessment of individual neurodevelopmental and behavioural conditions; this would be impractical, unfeasible and simply a waste of resources.

The development of a single, comprehensive, yet user-friendly, guideline that considers broad neurodevelopmental assessment would be of greater use for clinicians working in this area. Once again, this may well be a natural corollary of the work to develop companion competencies across the professional groups involved in neurodevelopmental and behavioural assessments, including assessment of ASD concerns.



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Revised Technical Report

Methodological Issues.

- We remain concerned that the section titled GRADING EVIDENCE FOR RECOMMENDATIONS is not sufficiently detailed or clear for the reader to understand how the system used for these guidelines is the same or different from recommended process according to NHMRC.
- How were the external reviewers chosen: by the Steering Group or NHMRC? This would be useful to state clearly, as well as indicating if they have past or existing research relationships with any of the steering committee.
- Are two external AGREE II reviews assured? Is there a plan for reviewers if the two specified reviewers are not able to complete in the timeline? This may be written in the methodological reviews, but we have not been provided with them. Similarly, is there a contingency plan in the event that the AGREE II reviewers suggest changes that have implications for more methodological work, or if feedback impacts decisions that have clinical and resource implications?
- We maintain our previous concerns arising from the unique methodology for evaluating and applying available evidence. While we understand this arises from the paucity of available evidence, the consequence of this situation is that the objectivity of the review of resource implications and other evaluation is even more critical. We recommend, if this is not already the case, that resource implications and other evaluation is conducted by a completely independent and different group of experts.

The process as described in the revised Technical Report is not clear on this point. Does the NHMRC choice include the 6 names provided to the Research Executive and as part of the NHMRC accreditation process, or do the NHMRC choose experts as a process that is independent of the Autism Guideline Group?

- The RECOMMENDATIONS FOR GUIDELINE DEVELOPERS do not seem to reflect the content of this section. The recommendations in this section seem to impact more broadly than just on the developers – NDIA and the Autism CRC.
- Appendix E appears to be available now. May we have a copy?