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Submitted via online form: https://redcap.link/ADGupdate_community_survey

Response to the Autism CRC consultation survey about the review of the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia* (the Guideline)

Survey Question Responses

150 words (strict maximum) permitted per response

Section 1: Sharing your views and experiences of assessment and diagnosis.
We acknowledge that capturing the lived experience of assessment and diagnosis is essential in the development and updating of the Guideline.
Section 2: Sharing your views about how specific aspects of assessment and diagnosis should occur
1. What are the most **important principles** (e.g., evidence based, strengths focused) that practitioners should follow in the assessment and diagnosis of autism?

• All current Guiding Principles (pp. 9-12) are important.
• The following (adapted) Principles from the *Draft National Guideline for Supporting Autistic Children and their Families* and others seem to also apply:
  o Culturally safe. Practitioners should acknowledge and respect values, knowledge, preferences and cultural perspectives, and reflect on their own cultural knowledge and competency in delivering assessment and diagnosis services.
  o Foundation for the future: Assessment and diagnosis should lay the foundation for future support/treatment goals that enable individuals with ASD to reach their full potential.
  o Timely, accessible: Each individual should be able to access assessment and diagnosis services when needed regardless of who they are, where they live, or how much money they have.
  o Continuity of care.

- Trauma informed.
- Refer to "family and family like" as a reminder about the diversity of family structures and who is considered 'family' by autistic people and those who support them.

2. What are the most important considerations for practitioners when **making a referral** for assessment and possible diagnosis of autism?

- The presence of a consistent practitioner from referral and throughout assessment, diagnosis and sharing of findings is an essential support for the individual being assessed and their family/supports.
- Cultural factors need consideration; how individuals are parented and expectations via social rules and norms differ considerably between different cultural backgrounds. The referrer should consider and note these factors when describing the symptomology of the individual they are referring.
- While referrers should consider the timing of an ASD assessment (e.g., the age of the individual and/or readiness of the individual/family to undergo assessment), a key statement in the Guideline is: "Early identification of, and intervention for, individuals with ASD is important in promoting positive longer term outcomes. If there is a persisting indication that ASD is a possible diagnosis, the primary healthcare professional is encouraged to refer for more specialised assessment of ASD concerns" (p. 26).

3. What are the most important considerations for practitioners when conducting an **assessment of functioning** that may lead to a diagnosis of autism?

- Guiding Principles (pp. 9-12) and considerations and recommendations already provided about assessment of functioning identify most of the important aspects needed to be able to identify client strengths, resources and supports that will enable them to reach their potential.
- For section 7.2 and Rec 23
  - Provide consistent information/language about functional assessment domains.
  - Include an initial assessment of mental state (versus social-emotional development) and home/family factors (e.g., parenting style, attachment disorder) that may impact client functioning, especially during assessments.
- For section 7.3 and Rec 26 – Note the importance of examiner rapport to ensure clients are comfortable and functioning well during the assessment to maximise validity. Even in settings where clients are comfortable, individuals with ASD can experience behavioural/mood difficulties that may impact assessment outcomes. This can be particularly challenging if clients have difficulties identifying and regulating their own behaviours/mood state.

4. What are the most important considerations for practitioners when conducting a **medical evaluation** as part of a possible diagnosis of autism? (150 words maximum)

- Guiding Principles (pp. 9-12) and considerations/recommendations already provided about medical evaluation identify most of what is important to address to identify medical conditions and/or comorbidities that might help explain the behavioural presentation and inform differential diagnosis and/or care.
- For section 8.2, Recs 33 & 34 and/or the Online Medical Evaluation Form Template
  - Add Injury Screening (e.g., prenatal substance use, head injuries)
  - Add Sleep Problems screening and the need to refer to a sleep specialist if unable to screen or screening raises concerns. Sleep problems can contribute to relevant behavioural presentations such as emotional dysregulation, sensory-related behaviours and the nature of social interactions.
- Include the Online Medication Evaluation Form Template in the Guideline as an appendix to increase practitioners' awareness of what is covered in the Medical Evaluation.

5. What are the most important considerations for practitioners when conducting **a diagnostic assessment** as part of a possible diagnosis of autism?

- Guiding Principles (pp. 9-12) and considerations/recommendations for diagnostic assessment identify many key issues for diagnostic decision-making.
- For sections 9.4/Rec 45 and/or section 12.7/Recs 69 & 70 – An appendix of co-occurring medical, psychological and neurodevelopmental conditions could aid the consistent application of Guidelines and increase awareness/education about co-occurrence, which is critical for differential diagnosis and future care and access to services.
- Limitations of ASD assessment instruments should be acknowledged by practitioners as part of valid interpretation of results. As per the Guideline, assessment instruments alone should not be used to make diagnostic decisions but rather weighed up in the context of the individual's developmental history, strengths and weaknesses.
- Practitioners should employ a hypothesis-testing approach to diagnostic assessment/differential diagnosis.
- Broadly detailing what comprehensive assessment includes (similar to Online Medical Evaluation template) could educate Guideline users about the scope and time required to conduct the assessment in a valid and reliable manner.

6. What are the most important considerations for practitioners to ensure the **safety and well-being** of individuals during the assessment and diagnostic process? (150 words maximum)

- Ensure cultural safety and trauma-informed care during assessment.
- Examiner rapport is critical to ensure clients are comfortable and functioning well during assessment to maximise validity. Even in familiar settings, autistic individuals can experience behavioural/mood difficulties that may impact assessment outcomes.
- ASD assessment/instruments can be anxiety-provoking for some clients e.g., high social engagement requirements. Examiners should be aware of this and modify approaches to support the client when needed but not compromise assessment validity.
- Examiners should be aware of the degree of awareness/acceptance of the client and/or family and provide support as needed.
- Provide post-assessment support to individuals not diagnosed with ASD. An assessment referral indicates difficulties in one or more domains - these should be addressed irrespective of an ASD diagnosis.
- Clinicians with knowledge about sexuality and gender identity (beyond sexual abuse and deviant sexual behaviour) are better placed to conduct respectful and well-being enhancing assessments.

Section 3: Sharing your views about the existing Guideline and the update

7. Is there anything you would like to see changed or clarified in the Guideline, when it is updated?

- The APS strongly recommends revising statements to correct the representation of the scope of practice of AHPRA psychologists with and without practice endorsements:
    - (p. 17, p. 19, Rec 37) To conduct a Single Clinician Diagnostic Evaluation, psychologists are recommended to have a practice endorsement in clinical psychology, clinical neuropsychology, and educational and developmental psychology.
    - (p. 53 re: adult clients) "A wide range of clinicians may be available to conduct a Comprehensive Needs Assessment and Consensus Team Diagnostic Evaluation; however, an adult psychiatrist, psychologist meeting the specified requirements or a medical practitioner meeting the specified requirements may be more appropriate for a Single Clinician Diagnostic Evaluation."

- (p. 54 re mental health assessment) "It is critical that mental health symptomatology is evaluated by a clinician with expertise in diagnosing mental health conditions, such as a psychiatrist or a psychologist."

8. Are there any questions or issues about the assessment and diagnostic process that you feel were not addressed in the original Guideline, that you would like to see addressed in the updated Guideline?

- Update DSM5 to DSM5-TR Autism Spectrum Disorder (psychiatry.org)
- Clarify Pathological Demand Avoidance (p. 50) which is recognised in the U.K but not in Australia. If an individual has this diagnosis, more information is needed about what to do in these circumstances in the Australian context.
- The decision to proceed to single clinician diagnostic evaluation - clarify the processes and who decides if practitioners involved in initial assessment processes have different views.
- Further information about managing consideration of ASD where a referral may not have originally noted ASD as a potential diagnosis, but the developmental history and initial assessment session indicate that ASD is a strong possibility.
- Clarify the pros and cons of the proposed National Register of ASG diagnoses, including potential impacts on individuals and families who may not seek assessment due to privacy concerns associated with registration.

9. If you haven't already identified these, what are the **barriers to implementing the Recommendations** in the existing Guideline?

- Individuals and/or families may not feel comfortable sharing their concerns with a potential referrer for assessment due to:
  - Stigma, discrimination associated with a diagnosis of ASD or co-occuring conditions that may be identified during assessment
  - Past experiences/trauma for clients associated with previous assessment or intervention services.
  - Limited knowledge of services and supports available during and post-assessment.
- Individuals and/or families may not be receptive to a referral recommendation due to their:
  - Mental health/mood state
  - Willingness to consider/accept a potential diagnosis of ASD
  - Concerns about undertaking a lengthy assessment process.
- Accessibility to assessment (and intervention) for regional, rural and remote clients.
- Financial barriers/affordability of assessment (and intervention) for individuals and/or families.
- Limited templates and resources – provide more (examples noted in previous responses) that are clearly hyperlinked within the document for awareness and ease of access for busy practitioners.

10. If you haven't already identified these, what are the **enablers to implementing the Recommendations** in the existing Guideline?

- Free access online – but requires ongoing promotion to all relevant practitioners.
- Well-established and connected medical and allied heath supports experienced in the field of neurodevelopmental disorders.
- Strong familial/psychosocial supports to enable access to assessment (e.g., financial, transport, location, motivation and support to engage with assessment and interventions).
- Clarify the training requirements expected for ASD examiners - perhaps in the longer term consider a credentialing approach that could be incorporated into postgraduate training and/or offered via CPD channels.

Kind regards,

Dr Zena Burgess, FAPS FAICD

Chief Executive Officer

Australian Psychological Society

The APS would like to acknowledge and sincerely thank the members who so kindly contributed their time, knowledge, experience and evidence-based research to this submission.