



Position Paper on the Diagnosis and Assessment of Autism Spectrum Disorders in Australia

Summary

All Australians are entitled to early, affordable and comprehensive assessment and diagnosis of autism spectrum disorders (ASD). As early diagnosis provides the best opportunity for positive outcomes, ASDs should be diagnosed in early childhood. Everyone who works with children in regional and metropolitan Australia ought to be aware of the signs of ASD and regularly monitor children as they develop, working to national diagnostic guidelines.

Background

As stated in our National Call to Action (April 2011), we call for access to timely and affordable diagnosis for both metropolitan and regional Australia that ensures:

- A national experience of no more than 3 months wait time for a diagnosis
- A national benchmark for a multi-disciplinary approach to diagnosis
- Extended Medicare rebates are available for diagnosis.

This will be achieved by:

- A national benchmark for the funding of the diagnostic process
- Comprehensive workforce capacity development strategies.

This is a critical priority for the following reasons:

- Families and individuals can wait up to 24 months for a diagnosis
- A time delay creates additional frustration and stress on family members
- Diagnosis is the critical starting point for families to access services
- Diagnosis is often a significant financial expense for the family
- Diagnosis can be difficult to obtain in rural and remote areas.

Principles

1. As Australian citizens, people with an ASD are valued and respected members of our community.
2. Whilst acknowledging that there is a wide range of available resources and models of practice in Australia, there is also a need for a consistent and reliable process to ensure the timely and accurate diagnosis of ASDs.
3. The recommended practice will support families and children with an ASD during what is potentially a very stressful time, by providing clear information about the assessment process.
4. Key aspects of recommended practice include:
 - acknowledging and responding to developmental and behavioural concerns as early as possible
 - a multi-disciplinary evidence-based process



- a partnership with parents
 - the provision of a written report with a clear diagnostic statement and recommendations for intervention
 - adherence to Internationally recognised diagnostic tools (DSM-IV–TR, ICD-10 and subsequent revisions)
5. The recommended practice of diagnosis and assessment includes four stages that:
- are broadly applicable to all individuals where an ASD is suspected
 - are applicable to individuals of all ages and developmental presentations
 - outline a process that may require an increase in complexity of assessment according to the needs of the individual
 - acknowledge that the assessment process may require a significant amount of time and expertise to complete and that some service may be needed before the final diagnosis is made.

Recommended Practice

1. General Professional Standards

International expert opinion suggests that recommended practice in the assessment of people who may have an ASD is a multi-agency, multi-disciplinary assessment involving:

- review of all existing information
- taking specific developmental and family histories
- focussed observation across more than one setting
- cognitive or developmental assessment by an educational or clinical psychologist
- full physical examination and application of relevant medical tests
- assessment of communication skills by a Speech and Language Pathologist with a particular focus on pragmatic language use
- assessment of mental health and behaviour
- other assessments appropriate to particular clients, investigating unusual sensory responses, motor difficulties or self care problems for example.

2. Stages of Diagnosis and Assessment

Recommended practice suggests that the diagnostic process for ASD is reflective of four stages:

- Stage 1: Identification of Concerns. The objective is to identify as early as possible children who may present with an ASD
- Stage 2: General assessment. The objective is to determine the child's developmental/intellectual functioning and language abilities and to identify any alternative medical explanations and coexisting health problems (eg, hearing and vision impairment) and to determine whether further assessment for ASD is necessary
- Stage 3: Autism spectrum disorder specific assessment. The objective is to determine whether or not an individual's clinical presentation is consistent with the diagnosis of an ASD. Where there is any



uncertainty regarding the accuracy of the diagnosis, evidence-based diagnostic tools such as the *Autism Diagnostic Observation Schedule*, *Autism Diagnostic Interview- Revised* or the *Diagnostic Interview of Social and Communication Disorders* must be used

- Stage 4: Feedback and Intervention Planning. The objective is to clearly communicate assessment findings to parents/individuals and initiate intervention planning. There must be the provision of a formal documented report on the diagnosis made and the instruments used. Families should be provided with effective support to facilitate effective pathways to service delivery.

Key Issues and Future Directions

The recommended practice outlined above in relation to professional standards and diagnostic practice is considered to be the most desirable outcome. However, there are a number of barriers and potential solutions that have been identified:

- Awareness: Greater awareness of the early signs of autism is required within the Australian community and amongst professionals to ensure the early identification of concerns. There also needs to be increased awareness and clarity around the available pathways to diagnostic investigation for all age groups and in all areas
- Workforce: There is a lack of adequately trained diagnosticians across Australia. A comprehensive workforce development strategy is required that will ensure ongoing professional development from undergraduate level and adherence to consistent national standards of practice. Paediatricians and allied health professionals working in diagnostic teams should be trained in the use of evidence-based diagnostic tools such as the *Autism Diagnostic Observation Schedule*, *Autism Diagnostic Interview- Revised* and/or the *Diagnostic Interview of Social and Communication Disorders*
- Affordability: Currently there is a Medicare rebate available for diagnosis up until the age of 13 years. However, in most cases the gap payment is still significant, making such services unaffordable for many families. There is a need for the existing Medicare rebates to be reviewed in relation to affordability and extended to all ages
- Access: Regional and remote communities are disadvantaged by location. Families and individuals should be able to access timely and affordable diagnosis irrespective of where they live
- Adults: Much of the recommended practice relates to children and adolescents. There is a need for the diagnostic process to recognise the unique needs of adults seeking an assessment
- Training Standards: There is a need to develop national regulations that require all diagnosticians to complete specific professional training and have extensive experience in the assessment and diagnosis of ASDs



- Quality Standards: Diagnosticians must be required to maintain recommended practice standards and up-to-date knowledge in the field
- National consensus: Currently, there is no national consensus on the approach to diagnostic practice within Australia. Collaboration between key industry bodies is required to develop a national approach that ensures consistent standards.

Conclusion

Further work is needed to ensure consistent standards of practice at a national level that will address some of the key issues highlighted.

Acknowledgements

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References

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