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AMA Submission to Select Committee on Autism

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Due to the broad nature of the inquiry's Terms of Reference, this submission by the Australian Medical Association (AMA) will provide a short covering letter along with our existing [Position Statement](#), which covers the areas of diagnosis (a); prevalence (b); Interaction between services (f); the National Disability Insurance Scheme (h); and funding for research (j).

The (AMA) has previously released [Position Statement Autism Spectrum Disorder – 2016](#), which we invite the Committee to consider as this position statement focuses primarily on Autism Spectrum Disorder in children.

Autism Spectrum Disorder Diagnosis

There is no biomedical test that can be used to diagnose Autism Spectrum Disorder. A diagnosis is typically made through the utilisation of screen tools and observation. This is reflected in *A National Guideline for Assessment and Diagnosis of Autism Spectrum Disorders in Australia*, produced by the Autism CRC.

In 2015, [an article](#) published in the *Medical Journal of Australia* suggested that children in Australia with Autism Spectrum Disorder are not being identified as early as they should be. These delays undermine opportunities for many children to benefit from appropriate early intervention. The reasons for delays in receiving a diagnosis and referral vary. For example, Local Area Health Services may recommend that general practitioners refer patients on for a range of tests and assessments prior to making a referral to a paediatrician. This can contribute to delays. Once a child receives a referral for a diagnostic assessment, workforce issues may further contribute to delays. There are limited numbers of paediatricians, child psychiatrists, and clinical psychologists who work in this field. These problems may be further magnified for children living in rural and remote areas where it may be even more difficult to access the appropriate clinicians to undertake a diagnostic assessment.

Recommendation 1: *Timely access to diagnostic assessment is vital. Governments, relevant Medical Colleges and professional bodies must ensure that there are a suitable number of clinicians and other professionals to provide proper access to diagnostic assessment for children suspected of having Autism Spectrum Disorder.*

Recommendation 2: *Once a child has received a diagnosis, prompt access to evidence based early intervention services should be a prioritised. In instances where a definitive diagnosis cannot be made, children suspected of having Autism Spectrum Disorder should still be able to access suitable early intervention services in an appropriate timeframe.*

Prevalence of Autism Spectrum Disorder

There is no comprehensive data on the prevalence of Autism Spectrum Disorder in Australia. Estimates are guided by prevalence data in comparable countries and smaller local samples. Utilising such data Autism Spectrum Australia (ASPECT) suggests that in one in 70 people in Australia are on the autism spectrum.

Interaction between services

Services provided for individuals and families impacted by Autism Spectrum Disorder sit across a broad range of sectors including (but not limited to) health, education, disability services and parent / consumer sectors. It is vital that each sector is recognised for their unique contribution but also that they work together to ensure the best outcomes for those impacted.

Recommendation 3: *Further exploration of models that support increased cross sector collaboration for individuals and families impacted by Autism Spectrum Disorder.*

The National Disability Insurance Scheme

Many children receiving support through the *Helping Children with Autism* package have been transitioned to the National Disability Insurance Scheme (NDIS), though the official end date has been deferred to 31 March 2021 due to the COVID-19 pandemic.

Concerns were flagged about the capacity for providing appropriate and timely support to those with Autism Spectrum Disorder in the early phases of the National Disability Insurance Scheme. Concerns continue, particularly around the wide variation of support packages provided to people with Autism Spectrum Disorder. While it is true that support needs can differ, there continues to be anecdotal stories of people with similar support needs receiving vastly different packages of support. There may be a range of factors contributing to this disparity but improving NDIS Planners understanding of Autism Spectrum Disorder is one aspect that may improve the situation. The 2020 *Review of the NDIS Act Report* makes a range of recommendations relating to improvements for the NDIS which may further enhance the interactions between individuals and families impacted by Autism Spectrum Disorder and the NDIS.

Recommendation 4: *Increased education and training on Autism Spectrum Disorder for National Disability Insurance Scheme Planners.*

Research funding

Australian research on Autism Spectrum Disorder is vitally important. This requires suitable investment. Funding of such research will ultimately improve our understanding of Autism Spectrum Disorder, effective interventions and the experiences of those impacted. It is worth noting that there continues to be significant amounts of misinformation about the causes, contributors and interventions relating to Autism Spectrum Disorder. Clear and regularly updated evidence summaries that seek to address this misinformation should also be a priority.

Recommendation 5: *Increased funding for Autism Spectrum Disorder related research, including research into therapeutic interventions. Summation of the evidence on non-causative factors should also be produced and promoted widely as part of efforts to reduce the spread of misinformation and misleading advice about Autism Spectrum Disorder.*

In summary, many Australian's are impacted by Autism Spectrum Disorder. It is important that we support individuals and families in accessing diagnostic assessment, treatment, and support in a timely manner. Supports may be required from a broad range of sectors and it is imperative that these sectors work together. Improvements in the funding of research and to the National Disability Insurance Scheme are

also likely to improve the experiences and outcomes for individuals and families impacted by Autism Spectrum Disorder.

AMA Recommendations:

1. Timely access to diagnostic assessment is vital. Governments, relevant Medical Colleges and professional bodies must ensure that there are a suitable number of clinicians and other professionals to provide proper access to diagnostic assessment for children suspected of having Autism Spectrum Disorder.
2. Once a child has received a diagnosis, prompt access to evidence based early intervention services should be a prioritised. In instances where a definitive diagnosis cannot be made, children suspected of having Autism Spectrum Disorder should still be able to access suitable early intervention services in an appropriate timeframe.
3. Further exploration of models that support increased cross sector collaboration for individuals and families impacted by Autism Spectrum Disorder.
4. Increased education and training on Autism Spectrum Disorder for National Disability Insurance Scheme Planners.
5. Increased funding for Autism Spectrum Disorder related research, including research into therapeutic interventions. Summation of the evidence on non-causative factors should also be produced and promoted widely as part of efforts to reduce the spread of misinformation and misleading advice about Autism Spectrum Disorder.

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Autism Spectrum Disorder 2016

What is Autism or Autism Spectrum Disorder?

Autism is a broad term used to describe developmental disabilities characterised by marked difficulties in social interaction, impaired communication, restricted and repetitive interests and behaviours, and sensory sensitivities.¹ Autism Spectrum Disorder (ASD) is a term that is used to recognise that the range of difficulties associated with Autism occur on a spectrum, with individuals impacted at varying degrees.

There is no reliable data on the prevalence of ASD in Australia. Estimates are guided by prevalence data from comparable countries. In the US, the Centre for Disease Control reports a stable prevalence of one in 68 children being impacted by ASD.² A more conservative estimate comes from the United Kingdom, where prevalence of ASD has been found to be one in 100 children.³ This more conservative estimate is often cited in Australia. Based on data from the ABS, this equates to approximately 230,000 children meeting diagnostic criteria for ASD.

Researchers are currently focusing on both genetic and environmental triggers for ASD, but the exact cause of ASD remains unknown. The AMA calls for ongoing research into the causes of ASD, and a summation of the evidence of non-causative factors to stop the spread of misinformation and misleading advice about the causes of ASD.

The AMA Position:

1. Early identification and intervention is vital

There is no specific medical (or biomedical) test that can be used to diagnose ASD. A definitive diagnosis is made via screening tools and observation. Current research suggests that ASD can be reliably diagnosed at two years; a recent international review found that diagnosis often occurs at three years of age.⁴ An analysis of Medicare data found that the most frequent age for diagnosis in Australia is 5.9 years.⁵ In a survey of parents and carers of children with Autism, 34 per cent reported waiting over a year for a diagnosis, and close to 20 per cent reported waiting for more than two years.

The data suggests that children in Australia with ASD are not being identified as early as they should be.

Due to brain plasticity, early identification of ASD can contribute to a significant improvement in outcomes. Children who are suspected of having ASD must be referred on for diagnostic assessment as soon as possible.

During the process of diagnosis, areas of deficits are likely to be identified. Following diagnosis, and based on identified deficits, children can be referred to a range of early intervention services that are tailored to meet their unique needs. The fundamental goal of early intervention is to reduce the impact of the disability. Early intervention also tends to lower the costs associated with the disability for families and the wider community.⁶

Delays in receiving a referral, combined with delays in receiving the diagnostic assessment, can result in children accessing early intervention services much later than is ideal. This diminishes the impact of the early interventions. Research and parent reports indicate that Australian children are encountering delays in the process of referral and diagnosis for ASD.

Recommendation: Effective and evidence-based treatments should be instituted as soon as possible to maximise the effectiveness of such therapies.

2. Workforce issues must be recognised

The drivers for the delays in receiving a referral and receiving a diagnosis are different. Once a child has received a referral for a diagnostic assessment, workforce issues may play a role. This is because a limited number of paediatricians, child psychiatrists, and clinical psychologists work specifically in the area of ASD. This problem is further magnified for children living in rural and remote areas where few, if any, clinicians provide diagnostic assessment.⁷ This can result in lengthy waiting times that may be detrimental for the child.

Recommendation: It is vital that governments, the relevant Medical Colleges, and professional bodies ensure that there are a suitable number of clinicians and other professionals to ensure timely access to diagnostic assessment for children who are suspected of having ASD.

Concerns about delays in accessing diagnostic assessment should not prevent a referral from being provided to a child suspected of having ASD.

3. Health, education, disability, and parent sectors must work together

ASD sits across a broad range of sectors including health, education, disability, and parent/consumer sectors.

Recommendation: It is vital that each sector is recognised for their unique contributions, but also that they work together to ensure the best outcomes for children and their families. Given that parents and teachers often spend lengthy periods of time with a child, medical practitioners should seek their insights and observations of children suspected of having ASD.

4. Guidance and research (GPs and interventions)

There are currently no Australian clinical guidelines that are concerned with the identification of ASD in general practice. This may be contributing to vastly different experiences for children who are suspected of having ASD. Recent research⁸ confirms this lack of consistency in ASD referral and diagnostic practices in Australia.

Recommendation: Suitable clinical guidance, possibly in the form of comprehensive guidelines or minimum national standards, should be developed in order to improve referral practices and diagnostic assessments for children suspected of having ASD. This material should be informed by international best practice and the latest research.

Recommendation: The AMA calls for ongoing research into the effectiveness of current and novel therapies.

Recommendation: All health professionals who interact with children should be encouraged to develop and maintain their understanding of early signs and symptoms of ASD.

5. Commitment that ASD will continue to be included as part of the NDIS

In many of the National Disability Insurance Scheme (NDIS) trial sites, there was unanticipated demand for access to NDIS support packages for children with ASD. At one site, almost half of those eligible for a support package had a diagnosis of ASD. It is unlikely that this level of demand was anticipated.

While the sustainability of the NDIS is not currently under threat, demand that outweighs resourcing may eventually undermine the Scheme in the longer term. One concern is that the demand will be addressed by narrowing the eligibility for children with ASD. Given the very real benefits of access to early intervention packages (offered through the Scheme), this is not ideal.

Recommendation: The Government must make a strong ongoing commitment that people who are impacted by ASD will have ongoing access to support through the NDIS.

Reproduction and distribution of AMA position statements is permitted provided the AMA is acknowledged and that the position statement is faithfully reproduced noting the year at the top of the document.

References

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- ⁸ Taylor, L., et al. (2016). *Autism Spectrum Disorder Diagnosis in Australia: Are we meeting Best Practice Standards?* Autism Co-operative Research Centre, Brisbane.