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AMA submission to the Autism Cooperative Research Centre consultation on draft of *The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia: A national guideline*

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Thank you for providing the Australian Medical Association with an opportunity to provide written comment on the draft version of *The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia: A national guideline.* In response to growing concern the AMA developed its own position statement on Autism Spectrum Disorder (ASD) in 2016, which contained calls for the development of appropriate clinical guidance for general practitioners (copy attached to submission). The work of the Autism Cooperative Research Centre (CRC), and the members of the Steering Committee, to develop such guidance is welcomed.

Further, the proposed two-tier approach to diagnostic assessment will feasibly reduce the time it takes for children with a typical ASD presentation to receive a diagnosis. Children with complex presentations will undergo more comprehensive diagnostic assessments, but given the variety of symptoms and presentations this is likely to be beneficial. A survey conducted by Autism Awareness Australia showed that over thirty per cent of families impacted by ASD had waited over one year for the diagnosis and twenty percent had waited for two years. This is not ideal and the AMA supports efforts to reduce this wait time. It will be important to monitor the impact that the two tier system has on the time it takes for families with typical and atypical presentations to receive a diagnosis.

General practitioners play an important role in providing referrals for the diagnostic assessment. The AMA has received reports that some diagnosticians require a standardised report from a child's school, or teacher, to be completed and provided as part of the referral documents. While there is no doubt that this sort of report provides unique insights, it is important to recognise that general practitioners have no real ability to compel a school, or a teacher, to provide such documentation. While the AMA does recognise the importance of the health and education sectors working together on ASD, it is important to acknowledge practical limitations such as this. General practitioners can not be responsible for the conduct of certain teachers and schools. The draft Guidelines do not provide any practical advice about how to resolve such concerns. A small section containing suggestions on improving engagement between health and education professionals, and how to approach any related problems, may be a beneficial inclusion.

As part of initiating an ASD assessment, the draft guidelines strongly encourage the administration of standardised developmental screening measures, three of which are highlighted to be used by

professionals such as general practitioners. The cost of purchasing the complete package of resources relating to each of these screening tools is over $1,000. This cost may be prohibitive for some of the designated 'referrers' including general practitioners.

It is vitally important that these guidelines are complemented by an appropriately funded dissemination strategy. All too often guidelines and other clinically relevant materials are uploaded to the internet and there is no meaningful effort to alert the relevant professional groups to the material. Specifically, it is worth alerting all Primary Health Networks of the Guidelines and working towards having the document included in their Health Pathways web portals which support the work of clinicians.

It would also be appropriate for the Guidelines to be complemented by targets for diagnosis timeframes, for example 70 per cent of children receiving a diagnosis within 4 months of initial presentation with concerns. While such targets may not be achievable initially, ongoing monitoring will provide a clear picture of progress and will unify all relevant professionals to work towards the same goal. It is also worth highlighting the importance of monitoring progress in those with a diagnosis of ASD. This involves base line measurements and then ongoing assessments, but it would help quantify the effectiveness of various interventions, for individuals, but also collectively. Such activities provide important insights, but are also time consuming and would require dedicated funding.

In summary, the AMA would like to reiterate the need to recognise the practical realities of the health and education sectors working together. Doctors and teachers are not able to compel each other to complete reports on materials that accompany referrals. The draft Guidelines must recognise this. While it is important to use well validated developmental screening measures, it is also important to recognise that in some instances the costs may be prohibitive.

Finally, the AMA would like to reiterate its appreciation to the Autism CRC and the members of the Steering Committee for their work on these Guidelines. In 2016 the AMA voiced concern about the lack of clinical guidance on ASD and we are pleased to see that such material will soon be available. We would welcome advice around the projected release date of the guidelines so that we can alert AMA members to this important resource.

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