

Response to Questions on Notice: Senate Community Affairs References Committee Inquiry into Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder, 16 September 2020

AMA Federal Council member Professor Stephen Robson gave evidence at the Inquiry's hearing on 16th September. Senator Griff provided six additional questions on notice which are answered below.

Question 1: Would it assist GPs and other physicians to have a specific Medicare item number for a FASD assessment?

The AMA would not support the creation of a specific Medicare item number for a FASD assessment. , Patients with chronic and complex healthcare needs should be treated as a whole person and able to access a fair rebate for a longer consultation that supports comprehensive care. Current Medicare rebates are inadequate and favour shorter consultations.

Alternatively, do you consider either or both of the following would assist:

a) That Medicare items for autism, FASD etc should be "applicable to neurodevelopmental presentations rather than linked to particular diagnoses", as put by Professor Doug Shelton during the 16 Sept hearing?

The AMA would tentatively support this approach, given that it may be an effective means to enable access to required care, and that linkage of item numbers to specific diagnoses should rarely ever be recommended.

b) Medicare items should be reviewed to "enable the provision of functional assessments that support NDIS access", as put by Dr Natasha Reid in her evidence during the 16 Sept hearing?

The AMA would support this approach. The AMA strongly supports improved access to the NDIS for people with FASD, including increased awareness among NDIS assessors of FASD's life-long effects. While the NDIS does not require a specific diagnosis to receive funding for services, the lack of awareness regarding FASD drastically reduces the availability of cohesive and comprehensive support services for people with FASD. Reviewing Medicare items to better provide the assessments that people with FASD need to access the NDIS is one important way to address this.

Question 2: What is the level of understanding among your members of FASD – is it routinely understood, able to be recognised – particularly if you have an adult presenting with comorbid conditions?

The AMA does not collect representative data on members' awareness of different conditions, but is anecdotally aware that understanding of FASD screening, diagnosis and management could be improved. As stated in the AMA's Position Statement *Fetal Alcohol Spectrum Disorder* – *2016*, "Due to the perceived

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stigma about diagnosing FASD, there can be a reluctance by health professionals to engage in conversations regarding the possibility of fetal alcohol exposure. This commonly leads to misdiagnoses including Attention Deficit Hyperactivity Disorder, Autism Spectrum Disorder, or other behavioural learning problems." Additionally, because FASD is a spectrum disorder – that is, it affects function in a range of ways from minimal to severe, it may be under or misdiagnosed, especially in adults. Improving awareness of FASD among medical practitioners will require a multi-pronged effort, with input from a broad range of bodies including the AMA and medical colleges.

Question 3: To assist with diagnosis for children in foster/state care, do you consider it could assist to record maternal alcohol consumption in the child's My Health record — or to allow clinicians to access the mother's My Health Record (MHR) for that information for children in care if that information is otherwise unavailable?

While documentation of family history is always an important aspect of comprehensive medical practice, and as mentioned is a vital component in the diagnosis of FASD, access to this information should be guided by fairness, need, and confidentiality. The inclusion of any information pertaining to the biological or legally appointed guardians into their children's medical record explicitly requires their consent. Clinicians should not have access to the health record of a biological mother for the purposes of assessing children in foster care without the informed consent of the mother in question. There may be some exceptions to this where the absence of this information would lead to foreseeable and unavoidable harm. In those circumstances, access to MHR information from the biological parents of children suspected of having FASD should be assessed on a case-by-case basis.

Question 4: How widely known, and used, is the Australian Guide to the Diagnosis of FASD among general practitioners and other health professionals who don't specialise in FASD diagnosis?

The AMA's 2016 Position Statement on FASD, which was published shortly after the Australian Guide to the Diagnosis of FASD, recommends dissemination and use of the Guide by all health professionals. It goes on to note that "All doctors who consult with children and adolescents should be aware of this tool and be comfortable in making a referral for a diagnostic assessment of FASD".

Anecdotal evidence suggests that General Practitioners are aware of the Guide and use it, enabling informed referrals for diagnostic assessment. Overall, the AMA is satisfied that the Guide supports awareness of best-practice FASD diagnosis. The AMA will continue to promote its recognition and use among medical practitioners, as well as advocating for an improved understanding of FASD in the general community.

Question 5: What is preventing the Guide of Diagnosis' broader dissemination to and use by health professionals, as the AMA would like to see?

In general, there are a number of barriers to diagnosing FASD that the AMA has raised previously. These include:

- The perceived stigma associated with alcohol consumption during pregnancy and the related difficulty of conducting sensitive conversations about this;
- The complex requirements of a best-practice FASD diagnosis; and
- The lack of inclusion of FASD in mainstream training requirements for medical practice.

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The AMA is not aware of any major barriers to the use of the Australian Guide to the Diagnosis of FASD. GPs have raised concerns with the length of the document and the lack of incentives to undertake CPD targeted at this area. CPD accredited online modules on FASD would assist in increasing awareness of FASD and the Guide for Diagnosis.

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