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SPEAKING NOTES

**LAUNCH OF AMA POSITION STATEMENT ON AUTISM SPECTRUM DISORDER
NSW PARLIAMENT HOUSE, SYDNEY
WEDNESDAY 7 DECEMBER 2016
AMA PRESIDENT DR MICHAEL GANNON**

***Check Against Delivery

I acknowledge the Gadigal people of the Eora nation, on whose land we meet today, and I pay my respects to their Elders past and present.

We are here today to launch the AMA Position Statement on Autism Spectrum Disorder.

More importantly, we are here to shine a light on how we as a community – governments, health professionals, parents, carers, and the general public – can do more with early diagnosis of autism, early intervention, awareness, and support.

We welcome special political guests:

- The Hon John Ajaka, NSW Minister for Disability Services;
- The Hon Walter Secord, NSW Shadow Minister for Health; and
- The Hon Sophie Cotsis, NSW Shadow Minister for Disability Services

A special welcome also to:

- Dr Sally Poulton, representing the Paediatrics and Child Health Division at the Royal Australian College of Physicians;
- Benison O'Reilly, the co-author of the Complete Autism Handbook;
- Rebecca Ho, the Executive Officer of Touched By Olivia – a prominent child disability advocacy organisation; and
- Stephanie Smith and Ian Rogerson - Board members of Autism Awareness Australia.

And I am joined in launching this Position Statement today by:

- Professor Brian Owler, former AMA President, public health advocate, neurosurgeon, Board Member of Autism Awareness Australia, and father of a child with autism; and
- Nicole Rogerson, founding Director and CEO of Autism Awareness Australia, a parent of a child with autism, and a tireless autism campaigner.

As we know, an increasing number of children in Australia are being diagnosed with Autism Spectrum Disorder, or ASD.

We don't know why. We don't know whether this is because our diagnosis practices are getting better, or whether there is an actual increase in the number of children developing ASD, or a combination of both.

We also don't yet fully understand the cause, or the main factors contributing to ASD.

But I am confident that, as time goes on, we will fully understand the condition, and be able to debunk the myths, misunderstandings, and complete misinformation being peddled about the causes and cures for ASD.

Parents of children with a potential ASD diagnosis have enough to deal with, without being bombarded with ridiculous and misleading misinformation.

We must protect and support all families affected by ASD, and provide them with guidance about what we know will help, and what won't.

We need ongoing research into the real causes and contributors to ASD, and treatments.

And we need action – and this Position Statement lays out that action.

First, we need early diagnosis and intervention. As medical practitioners, we understand that timing is critical.

The sooner we can identify a problem or concern, the better. This is particularly true of ASD, as the brain's ability to respond and remodel itself means early intervention can make a huge difference to the outcome for children.

There is no specific biomedical test for ASD. It can't be diagnosed with a blood test or a scan - not yet anyway.

This means that many children are not diagnosed as quickly as possible.

ASD can be reliably diagnosed at two years.

But an analysis of Medicare data, published in the *Medical Journal of Australia*, shows that Australian children are most commonly being diagnosed at around six years of age.

Children living in similar countries are commonly receiving their diagnosis at around three years of age. For some, it is even younger.

A survey conducted by Autism Awareness Australia found that 34 per cent of families waited more than a year for diagnosis, and close to 20 per cent waited more than two years.

So our first recommendation is that:

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

That's easy to say. But how do we get there?

The number of paediatricians, child psychiatrists, and clinical psychologists working specifically in ASD is limited.

This problem is magnified in rural and remote areas, where few, if any, clinicians can make the diagnosis.

As telehealth technology improves, specialist teams may be able to make assessments via secure video conferencing connections.

But we also need to address the workforce issues.

So our second recommendation is that we call on:

Governments, the relevant Medical Colleges, and professional bodies to 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.

But doctors are not the only important factors in diagnosis and intervention.

The health, education, and disability sectors, and families must work together to ensure the best outcomes for children.

Teachers, parents, carers, and others who spend extended periods with children can offer unique and valuable insights into a child's development that may otherwise be missed during diagnosis.

So our third recommendation is that:

Medical practitioners should talk to teachers and families to seek their insights and observations of children suspected of having ASD.

And we must support GPs to know how, when, and where to refer a child for diagnosis.

GPs are usually the first health professional that a parent will confide in about their concerns for their child.

Yet Australia currently has no nationally consistent guidance for GPs about when to refer children on with symptoms of ASD for a more specialised assessment.

This may be contributing to vastly different experiences for individual children.

So, to combat this, we make three recommendations:

- **That comprehensive guidelines and/or national standards, be developed to improve referral practices and diagnostic assessments for children suspected of having ASD;**
- **That there be ongoing research into the effectiveness of current and potential therapies; and**
- **That all health professionals who interact with children are encouraged to develop and maintain their understanding of the early signs and symptoms of ASD.**

Finally, many of you will be aware of the transition to the National Disability Insurance Scheme.

Those diagnosed with ASD are among the largest groups to seek access to the NDIS. And it seems likely that the numbers will grow.

It is vital that those affected by ASD, and their families, remain confident that the Scheme will continue to provide these tailored support packages, now and into the future.

There cannot be any narrowing of eligibility criteria for people with ASD to access the NDIS.

Our final recommendation is that:

The Government must make a strong and ongoing commitment that people impacted by ASD will have ongoing access to the NDIS.

The AMA recognises that the medical profession plays a critical role in supporting families, from the moment they first suspect something is different about their child, to diagnosis, and intervention.

The AMA's Position Statement sets out specific actions that will give us the tools we need to provide that support in the best possible way.

We also recognise that there are broader issues that affect children and families impacted by ASD, and we intend to undertake advocacy on these matters too.

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