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Department of Social Services GPO Box 9820 Canberra ACT 2601

Developing the National Autism Strategy

The Municipal Association of Victoria (MAV) welcomes the opportunity to provide our response to the National Autism Strategy – Discussion Paper.

The MAV is the peak representative and advocacy body for Victoria's 79 councils. The MAV was formed in 1879 and the Municipal Association Act 1907 appointed the MAV the official voice of local government in Victoria.

A key responsibility of Victorian councils, and one they have a long and proud history of delivering, is strategically planning for the health, wellbeing, safety, connection to culture, access, participation, and development of its residents. Councils take a whole-of-community, whole-of-system approach to building community strength and addressing the underlying causes of inequity and vulnerability.

With Victorian local government a critical partner in the delivery of services and programs that support children, families, and communities, we want to flag the MAV and the Victorian local government sector as interested stakeholders in the strategy review.

The MAV works in partnership with the Victorian Government on policy directions, funding and continuous improvement for maternal and child health services in conjunction with other early childhood services.

In reviewing the Key Themes of the Discussion Paper, the MAV will primarily contain our response to the issues raised in Key Theme 3 *Diagnosis, Services and Supports*, particularly as the paper points out "Maternal and child health nurses, general practitioners, early childhood education and care professionals and teachers play an important role in assessing whether a child, young person or adult may need further screening and referral for an autism assessment. Professionals often need greater capability in recognising characteristics or behaviours associated with autism."

In 2018/19, the Victorian Government rolled out training for Maternal and Child Health (MCH) nurses in the early identification of autism spectrum disorder (ASD) in children. The Monitoring of Social Attention and Communication (MoSAIC) in infants and toddlers' program. The Victorian Government and councils continue to support this professional development for the MCH workforce via online modules developed by the Olga Tennison Autism Research Centre (OTARC), La Trobe University, Melbourne.

This program has provided MCH nurses in local government with the skills to confidently identify the early signs of social communication delay in children during their routine 12-, 18- and 24-month Key



Age and Stages health checks. As stated by Dr Joesphine Barbaro about the program "We know that 50 per cent of parent's voice concerns before 12 months, so our training is closing the gap between parents' first concerns and a definitive diagnosis." "We're also empowering nurses to not only spot the early signs of possible autism in infants and toddlers, but to jointly discuss these signs with parents and provide referral pathways with empathy and support."

The key initiatives of the program were:

- To increase the early identification of ASD in young children
- Build MCH nurse skills to identify ASD and provide appropriate referrals and
- Support families to better support children earlier in managing ASD, to optimize long-term educational and social outcomes.

The MoSAIC training for MCH nurses also aims to address the issue of misdiagnosis and underdiagnosis in female infants and toddlers, as noted in the Discussion Paper Key Theme 2, *Economic Inclusion.* This training increased the skill, confidence and knowledge in relation to gender variations for MCH Nurses and thus improves early identification and referral.

Despite early identification of the 'high likelihood" of autism and referral, access to assessment and diagnosis is delayed, due to a lack of available assessment services. Families face extensive waiting lists to access support like allied health/early intervention or pediatricians and in some instances, no waitlist is available to access.

Costs of private over public options can push access out of reach for families, where NDIS does not cover the cost of the assessment, therefore discriminating based on financial circumstances.

Integral Council services such as Maternal Child Health (MCH) and Preschool Field Officer (PSFO) play a vital role in supporting children and their families. Current best sector practices include but are not limited to; MCH In-home visits for vulnerable families or those not able to travel, EMCH (Enhanced Maternal Child Health) support to facilitate access to early intervention, PSFO Educator capacity building, and PSFO local service navigation.

The limitations, fragmentation, and lack of coordination of programmatic outputs and funding in the early years, fails to recognise children and families need earlier support to have their needs assessed and addressed. For example, the limitation of the Kindergarten Inclusion Support funding only focuses on those children with ASD that pose 'significant danger to self or others' – however the child and their families have great support needs to assist them with inclusion and integration into society successfully. Educators are often not attempting the KIS (Kindergarten Inclusion Support) application process, due to feeling overwhelmed by the length and requirements of the application process, another barrier to diagnosis.

In our experience, the decisions families make about autism diagnosis and treatment are influenced by the family's cultural background. Families may see delays in language/communication and social skills, as a normal process their child encounters as he or she moves through developmental stages. As a result, they may not identify important but subtle queues for ASD (lack of pointing, lack of imitation, lack of eye contact, and a lack of socially appropriate behavior); instead, they may associate ASD with repetitive language, ritualistic behavior, and gross delays in motor skill development. In effort to address this issue, Victorian local government is working with the State Government to trial cultural workers across universal early childhood services.

In describing what better access to diagnosis, services and support looks like for Autistic people thoughts include; A funded, smooth, and consistent referral pathway, for ASD Diagnosis and supports access for all families.

The MAV would like to see opportunities for Victorian Councils to be included in contributing and identifying areas of reform and removing barriers for our ASD community, to support their participation in Australian society.

