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## **Submission to the Inquiry into Services for People with Autism Spectrum Disorder**

Merri Health welcomes the opportunity to provide feedback to the Inquiry into Services for People with Autism Spectrum Disorder.

Merri Health creates healthy, connected communities through local health services for people at every age and stage of life. Our approach is holistic, addressing the medical, social, environmental and economic aspects that affect health, with services spanning across children and young people, carer support, chronic disease management, mental health, disability support, population health and aged care. We've been the trusted health service of local communities for over 40 years.

As a not-for-profit organisation, our focus is on partnering with people, responding to local needs, and strengthening the health of entire communities. Merri Health has a focus on addressing health needs based on inequalities, and consequently is committed to advocating for, and addressing gender equity in any way we can.

Merri Health is the provider of Child Health Services and Early Childhood Intervention Services which support children aged 0-6 with developmental delays and disabilities. There is a significant prevalence of Autism Spectrum Disorder (ASD) with the children we support. As such, Merri Health's submission to the 'Inquiry into Services for People with Autism Spectrum Disorder' focuses on children 0-6 years of age with ASD when responding to the key points of enquiry noted in the terms of reference.

### **The prevalence of autism spectrum disorder in Victoria:**

Our experience in working with children and families affected by ASD, developmental delays and/or childhood disabilities indicates:

- It is difficult to gauge the prevalence of ASD as the parameters for diagnosis are quite unclear, subjective and often inconsistent, even amongst skilled paediatricians.

- Approximately 70% of children supported by our Child Health Service appear to be undiagnosed high functioning ASD. A similar percentage of children supported by our Early Childhood Intervention Service are diagnosed with ASD.
- The prevalence of other disabilities can often influence a diagnosis of ASD. For example, some children diagnosed with auditory processing issues and sensory integrative disorders or Attention Deficit disorders are actually on the Autism Spectrum. Conversely some children diagnosed with ASD in their early years, actually have a developmental delay which does not become evident until at a later age.
- Alternatively, so many of the issues for children on the spectrum manifest themselves initially as behavioural issues leading to years of investigations, misdiagnosis and incorrect treatment. Furthermore, as it is a spectrum, presentations can vary widely as no two children present with identical issues.
- Limited access to diagnostic services means some families fail to access adequate and appropriate supports, whilst a second group of people are in denial of their child's presenting issues and are unwilling to access formal assessment even though concerns might have been raised by multiple professionals.

**The availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services:**

Our experience to date leads us to formulate the following conclusions:

- Whilst there are adequate amounts of therapeutic services for children with a clear diagnosis of ASD there is often poor knowledge about access pathways from both professionals and families.
- Whilst therapeutic interventions are reasonable there is a significant deficit in behaviour support service options for children with ASD and in particular there is limited access and availability to group based supports for children with ASD.
- There is currently no measure of accountability regarding the type of therapies that are used to support children with ASD. This is particularly the case in private practice where the model of service offered is at times counterproductive. Particular concerns centre upon 'unproven' services made available or recommended, sometimes at a huge cost to families. There needs to be tighter surveillance and auditing of what is being offered across the health and community sector. Current evidenced based practise and government policy directions promote settings based models of therapeutic intervention being delivered in inclusive settings, i.e. such as the

family home, whilst most private services offer office based support and models which undermine the parent /child relationship leading to disempowerment of parents.

- The quality of some services is questionable. There are a number of service providers who target vulnerable parents who are desperate to find a 'cure' for their child. Service interventions need to incorporate supporting and training parents to cope with their child's condition and management of this in the home environment. Models that create dependency are not appropriate as the aim should be to build the capacity of parents to meet their children's needs.
- Given the complexity of the current service system, professionals and parents often struggle to navigate their way through the maze. Families particularly experience the system as a minefield with inconsistent messages. This often leads to confusion when it comes to selecting appropriate service options for their children.
- Respite for parents is a key area of need, particularly in the first 6 years, it is extremely difficult to locate or access this service for parents/caregivers with a child with ASD. Parenting any child can prove to be difficult, parenting a child with autism is even more complex and challenging. Parents need 'time out' and there are few services offering this support. The consequences of parents being unable to access respite can lead to family breakdown and parental mental health issues.
- Once children with ASD reach school age there are even fewer service options including limited access to school holiday programs and after school care.
- There is a problem accessing appropriate physical activities for children with ASD as they do not often fit in with traditional popular team sports.
- The diversity within ASD is problematic in itself, for example every child with ASD will present in different ways and with diverse needs. There is a need to do away with the ASD 'label' and work with the needs of children and families, a need for good individualised practical support. Service provision needs to be child and family centred.
- There is a lack of integration and communication across government and community services. Relationships are usually dependent upon the strength of personal connections as opposed to clarity of expectations regarding collaboration, service partnerships and referral pathways between sectors and services.
- Teachers and childcare workers in the education system are poorly equipped to manage and care for children with ASD. Training for these professionals general encompasses early years but does not address caring for children with disabilities. The introduction of a practicum in early intervention should be part of the training module for early childhood educators.

## **The adequacy of services to be provided under the National Disability Insurance Scheme (NDIS):**

This is somewhat unknown as we are not entirely clear about what services will and will not be provided at this stage under NDIS. The transition of early intervention services into the NDIS poses a number of issues as formal diagnosis of children with ASD at early years is challenging. The National Disability Insurance Agency is still developing the referral pathway for children into the scheme and indicators to date signify that additional supports will be made available for parents seeking to navigate the system and support planning for accessing children disability service supports.

Our understanding and analysis to date lead us to form the following deductions:

- All children with ASD engaged with early intervention services at the time of roll out will be eligible for NDIS. However it will be more difficult for those with mild or high functioning ASD to meet the criteria for NDIS when they undertake their 12 month reassessment or when they transition out of Early Intervention Services. It will also prove difficult for those families with children currently on waiting lists to be screened to know what they can expect from services into the future.
- Our current experience is that some parents are reluctant to seek a diagnosis which 'labels' their child. The criteria for early intervention currently is flexible and does not always require a diagnosis, however, in an NDIS environment diagnosis is critical to receiving support. There is significant concern that children and families will no longer have access to essential services because of the rigidity of the NDIS eligibility parameters.
- Current diagnosis is inconsistent and it is essential that this be addressed under the NDIS. The current assessment process for ASD is long, complex and costly with families required to navigate multiple services. In order for all children on the spectrum to have equitable opportunity to access support under NDIS there is an urgent need for more locally based, cost effective and streamlined diagnostic services manned by specialists experienced in this field.

## **The projected demand for services in Victoria:**

Based on our experience over many years, a heightened and informed awareness has seen an increase in parental concern and help seeking behaviour, however patterns in formal diagnosis have not followed. As the diagnostic process is refined and streamlined, particularly within the NDIS system, we predict an increase in demand for services.

The formalisation of diagnostic services due to potential stringent eligibility requirements funding under the NDIS has the potential to contribute to an increasing demand for service.

## Conclusion

Unfortunately there is still a lack of community acceptance of difference. ASD should be raised to a level of awareness in the community similar to the focus on family violence or gender inequality. We neglect to value children with ASD in our community and adults with ASD are even less recognised or catered for. ASD is a condition that will not disappear and it has ramifications in primary schools, secondary schools, early adult and later adult life. Integrating children into a tolerant and informed community will change the outcomes for that child and their family and ultimately lead to better long term health outcomes inclusive of optimum involvement in social and economic participation. As is well documented investment in early years leads to far better long term health outcomes and decreases the long term economic health burden.

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