

## Submission to the Senate Inquiry into Effective approaches to prevention, diagnosis and support for FASD

### Neurodevelopmental and Behavioural Society of Australasia (NBPSA)

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## The NBPSA

The Neurodevelopmental and Behavioural Paediatric Society of Australasia (NBPSA) is a membership organisation for doctors who work with children, and their families, who have problems impacting development and behaviour.

Established in 2012 the NBPSA includes over 500 paediatricians, paediatric neurologists, psychiatrists, general practitioners, career medical officers and specialist physician trainees.

As an affiliate of the Royal Australasian College of Physicians, the NBPSA provides the highest level of physician expertise in caring for children with neurodevelopmental and behavioural conditions. The Society runs professional seminars and conferences for members and allied health professionals working in neurodevelopmental and behavioural paediatrics and works to promote the most up to date clinical practice across Australasia.

Having no single diagnostic focus ensures that the Society provides individuals, organisations and governments with impartial, consensus medical advice on the complex array of behaviours, assessments, diseases and interventions involved in neurodevelopmental and behavioural (NDB) paediatrics.

Recommendations have been provided to enhance prevention of Fetal Alcohol Spectrum Disorder (FASD) and support care for children with this neurodevelopmental challenge. The NBPSA is keen to work with government to help reduce FASD in the community, maximise opportunities for children with this neurodevelopmental condition to be the best they can be and to reduce the impact of lifetime disability.

## Recommendations

FASD is a preventable neurodevelopmental disorder. It is a complex condition requiring special skills to assess, diagnose and treat.

Australia has some of the highest rates of prenatal alcohol use in the world.<sup>1,2</sup> A new focus on community education is required to prevent alcohol consumption for those who are pregnant or planning a pregnancy.

It is important that children affected by pre-natal alcohol exposure, and their families, have access to the right level of expertise and care. Due to complexity of the condition and the considerable family stigma associated with a diagnosis of FASD, children require skilled clinicians working as part of multidisciplinary teams for appropriate assessment, diagnosis and treatment. This is particularly so for children from vulnerable populations (eg those in out of home care, families with cultural and literacy barriers and those with social determinants of health risk factors).

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<sup>1</sup> Colvin L, Payne J, Parsons D, Kurinczuk J, & Bower C. (2007). Alcohol consumption during pregnancy in non-Indigenous West Australian women. *Alcoholism: Clinical and Experimental Research*, 32, 276–284

<sup>2</sup> Popova S, Lange S, Probst C, Gmel G, Rehm J. Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis. *The Lancet Global Health* 2017; 5(3): e290-e9

## NBPSA Recommendations

The NBPSA recommends

1. A new focus on community education for women of childbearing age, to prevent alcohol consumption for those who are pregnant or for unplanned or planned pregnancy, noting harm for the baby and potential for FASD.
2. Implementation of population health strategies to reduce the stigma associated with the diagnosis for children with FASD and their families.
3. Recognition of the complexity of diagnosis and management of FASD as one of a number of neurodevelopmental and behavioural conditions with overlapping signs and symptoms, such that FASD is only one diagnosis considered amongst many potential differential diagnoses.
4. Facilitation of assessment, diagnosis and treatment of FASD by skilled paediatricians as part of multidisciplinary teams, who have expertise not only in FASD diagnosis but in potential differential diagnoses.
5. Enhanced support for families where risk factors impact in terms of parental capacity to advocate for their child's needs. This includes at risk populations (eg Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, people living in rural and remote locations and children in out of home care) as well as families with individual risk factors (eg parental mental ill-health, poor health literacy, financial adversity).
6. Ensuring alignment between government supports and strategies for children and families with NDB conditions, including FASD, with creation of a new Child and Family Development Framework that:
  - a) aligns National Disability Insurance Scheme supports to a child's functional and care needs. The Framework should allow for initial access based on need (not diagnosis) with potential for agile escalation and de-escalation of supports across periods of stress and key transitions, such as starting at school, from childhood to adolescence and then to independent living
  - b) supports early intervention for families of very young children by providing families with a Key Worker who can build the family's capacity to support their child's development and manage resources for necessary activities including case conferences, travel to home and childcare.
7. Development of a joint Health Agency and National Disability Insurance Agency approach to support the Framework including:
  - a) local Action Networks for responsive, agile management of children in urgent need
  - b) timely access for children with NDB conditions and disabilities
  - c) addressing the interface issues between the NDIS and neurodevelopmental-behavioural services within Health and Education, and in particular establishing a coordinated approach to assessment and review of a child's needs
  - d) promoting consistency across policy frameworks for assessments and data collection with development of valid and reliable measurements to evaluate the outcomes of NDIS and Health funded interventions and support plans
  - e) development of a transparent set of standards and competencies for planners and service providers

## FASD: A complex NDB condition

Alcohol consumption during pregnancy is associated with adverse impacts for development of the foetal brain.

Research on prevalence of FASD in Australia is limited with some jurisdictional based studies reporting birth prevalence rates of Fetal Alcohol Syndrome of between 0.01 and 0.68 per 1000 live births. Higher rates of this condition have been found among Indigenous communities, likely reflecting socioeconomic factors and patterns of alcohol use.<sup>3</sup>

### Assessment and Diagnosis

FASD is a complex neurodevelopmental condition requiring confirmation of severe impairment in multiple developmental domains for diagnosis. The developmental and behavioural features of FASD are also present in other relatively common neurodevelopmental conditions, such as Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder (ADHD). In addition, some of the clinical features are also found in children exposed to early life trauma.<sup>4</sup>

It is most important that planners and policy makers are aware that the diagnosis of FASD, or the identification of concerns about FASD, does not in itself determine or guide the treatment or support needs of an individual.

Many medical diagnoses describe a defined range of signs and symptoms, support needs and treatments. These diagnoses can appropriately be used to guide optimum management within the health care system and to identify the type of supports required from disability services and schools. It is not appropriate for a diagnosis of FASD to be used in this way.

FASD is a medical diagnosis defined by presumed cause; prenatal exposure to alcohol. The impact of this exposure may present as a wide range of signs and symptoms, severity and needs, many of which can also be caused or influenced by other conditions.

Any assessment of FASD concerns must be undertaken in the context of a broader neurodevelopmental and behavioural assessment which will typically consider functional and cognitive capacity, family history, social and environmental circumstances and a relevant range of other possible diagnoses. Paediatrician input is needed and for more complex presentations, particularly for children from vulnerable populations, clinicians will need to work with a multidisciplinary team for appropriate assessment and diagnosis (where available) and plan appropriate treatment and support on an individual basis. Complex presentations frequently arise where children are in out of home care and in families with cultural or literacy challenges and those living in challenging social circumstances.

Access to treatment, support and assistance for children with FASD and any other neurodevelopmental and behavioural condition, should be based on an assessment of their clinical needs, functional capacity and abilities, not simply a diagnosis. For some children, there may be an urgent need for intervention before an accurate diagnosis can be formulated. As children change rapidly during their development, treatment and support plans also need to be individually tailored and adjusted during their developmental trajectory and as their circumstances change.

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<sup>3</sup> Burns et al 2013 in <https://www.aihw.gov.au/reports/alcohol/alcohol-tobacco-other-drugs-australia/contents/impacts/health-impacts#injectionrelatedharms> accessed 30 November 2019.

<sup>4</sup> Price A, Cook PA, Norgate S, Mukherjee R. Prenatal alcohol exposure and traumatic childhood experiences: A systematic review. *Neurosci. Biobehav. Rev.* 2017; 80: 89–98.

Improving access to and accuracy of diagnosis will be an important factor in further building understanding of the prevalence of FASD and in assessing the effectiveness of the National FASD Action Plan 2018-2028, and other preventive strategies over time.

### A new focus on prevention and reducing stigma for families

Given children with FASD have a preventable brain injury there is a clear need to ensure every effort has been made to reduce the risk of pre-natal exposure to alcohol.

The proportion of women who exceed the lifetime alcohol risk guidelines varies by age and between population groups in Australia:

- 7.5 percent of younger women (aged 18–24) exceed the lifetime alcohol risk guidelines, compared with 11 percent of women aged 65–74
- 12 percent of women living in the most disadvantaged areas (first quintile) exceed the lifetime alcohol risk guidelines, compared with 7.8 percent of women living in the least disadvantaged areas (fifth quintile)
- 10 percent of women living in *Outer regional and remote* areas exceed the lifetime alcohol risk guidelines, slightly more than women living in *Major cities* (9.2 percent)
- 11 percent of Aboriginal and Torres Strait Islander women exceeded the lifetime alcohol risk guidelines in 2012–13. After adjusting for differences in age structure, there was no difference in the rates of risky drinking in Indigenous and non-Indigenous women (about 10 percent).<sup>5</sup>

The National Drug Strategy Household Survey 2016 showed 56 percent of pregnant women abstained from drinking alcohol during their pregnancy, an increase from 40 percent in 2007. The remaining women reported that they reduced their drinking during pregnancy (43 percent) compared with when they were not pregnant, and one percent reported drinking the same.<sup>6</sup>

The 2009 National Health and Medical Research Council Australian Guidelines to Reduce Health Risks from Drinking Alcohol, state that for women who are pregnant or planning a pregnancy or breastfeeding, not drinking is the safest option.<sup>7</sup>

There is a need to consider the best approach to educate women of childbearing age so that alcohol consumption in both unplanned and planned pregnancy can be avoided

As noted by a Developmental paediatrician in a recent FASD educational video *“Indeed for most of the children that we see the exposure to alcohol was inadvertent because mum didn’t realise she was pregnant, wasn’t planning to get pregnant, and stopped drinking as soon as she found out she was pregnant”*.<sup>8</sup>

Population health strategies are also required to help reduce the stigma of diagnosis of FASD for children and their families. Families need specialised supports during assessment and diagnosis to help keep focus on the child and how s/he can reach their potential. This is very difficult for families or communities where blame for the condition tends to rest with the mother.

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<sup>5</sup> ABS 2013; ABS 2015a; ABS 2015b <https://www.aihw.gov.au/reports/men-women/female-health/contents/lifestyle-risk-factors> accessed 30 November 2019

<sup>6</sup> AIHW <https://www.aihw.gov.au/reports/alcohol/alcohol-tobacco-other-drugs-australia/contents/impacts/health-impacts#injectionrelatedharms> accessed 30 November 2019

<sup>7</sup> NHMRC 2009

<sup>8</sup> <https://www.fasdhub.org.au/fasd-information/understanding-fasd/fasd-hub-videos/> accessed 30 November 2019

## Children with FASD and the NDIS

Children with FASD need lifetime support and early access to the National Disability Insurance Scheme is key to helping children and families be the best they can be. The following outlines the NBPSA position on NDIS supports for children with neurodevelopmental and behavioural challenges including those with FASD.

The NBPSA does not support the requirement for diagnosis as a gateway to the NDIS.

Neurodevelopmental and behavioural diagnoses often overlap and interact and for many children an accurate diagnosis may not be clear, or possible, early in their life course. A much better approach is a functional and care needs-based approach.

It is typical that neurodevelopmental and behavioural conditions lie on a spectrum. A child at one end of the spectrum may need no support or minimal supports to reach their potential while another child, with the same condition, may have complex problems that require lifelong care.

There are unintended consequences arising from the current system where complexity and severity creep has led families to focus on, and emphasise, their child's worst day rather than their best day just to meet NDIS access requirements. Further, support needs may escalate for a child with FASD as they go through puberty and despite being foreseeable, this escalation may not be funded due to their previously documented level with the NDIS.

A focus on diagnosed disability is also at odds with the opportunity for short bursts of early intervention at critical developmental stages, with the aim of preventing considerable future disability. NDIS planners need to be 'developmental disability aware' so that support and care of children with broader neurodevelopmental challenges can be planned and interventions coordinated with health and other service providers, particularly in situations where the diagnosis is uncertain or yet to be determined.

### A new Child and Family Developmental Framework

Adults with disability often have fixed disorders and predictable trajectories. It is often impossible to put this lens on a child who will have fluctuating support needs across the predictable transition times from infancy through to adulthood.

Children with neurodevelopmental and behavioural challenges have disabilities arising from complex, brain-based medical conditions. These conditions can change rapidly as a child develops: the child's support needs may also change significantly through various stages of learning and development.

The original design of the NDIS did not consider the special needs of children. While the Early Childhood Early Intervention (ECEI) approach was a well-intended attempt to address this oversight, it has proved not to be fit for purpose.

A new Child and Family Developmental Framework is needed to provide access to baseline NDIS supports with intermittent escalation of support at times of stress or transition. This needs to continue to be available through childhood and adolescence, rather than stopping at 6 years 11 months, with increasing family and young person autonomy (choice and control) aligning with the level of supports provided over time.

Getting it right early can make a big difference to a child's development and a family's ability to cope.

## NDIA and Agencies: an opportunity for collaboration

There is a need to establish stronger connections between the health sector, the NDIS and related government agencies for FASD and other NDB conditions the give rise to disabilities in children.

Prior to transfer of state and territory disability services and funding to the Commonwealth, local disability networks supported good communication and action for children in immediate need, particularly those at risk of harm. An unintended consequence of implementation of the NDIS has been the erosion of these networks and reinforcement of government silos. The result has been that families are now expected to bring everything together and they are getting lost.

Cross agency networks are critical to good care. For example, a review found that nine in ten Western Australian youth detainees had a severe neurodisability.<sup>9</sup> Children with psychosocial conditions and complex neurodevelopmental and behavioural challenges require specialised collaborative care and review. An approach is needed that facilitates NDIS, Health, Education, Justice and other programs working in an efficient and coordinated manner to support children and families. Connecting the dots to reduce psycho-social adversity is likely to reduce functional impairment. For example, a family who has a house and food and mental health supports is less likely to be overwhelmed by, and more likely to better manage, their Autistic or intellectually disabled child's tantrums.

These complex interactions and constant changes present unique challenges for the child and their families, clinicians, educators and disability planners. Each person experiences the opportunities presented through their developmental years just once in their lifetime. Yet there is no coherent policy environment that allows experts across health, education, justice and disability to share their expertise, collect common data or evaluate and measure common intervention strategies.

In addition, the growing pre-occupation with diagnosis across non-health agencies has diverted attention from away from careful, considered functional and needs-based assessment. A multi-agency approach is required to ensure informative, clinically valid and consistent assessment approaches are taken across agencies. Over time, this would be expected to improve coordination of care planning and the evaluation of outcomes for future system improvements.

This siloed policy environment has exacerbated the frustrations experienced by carers, families and adults who have grown up with NDB challenges. It also reduces capacity for finding, or building the evidence needed to inform, sensible solutions and the effective allocation of available resources.

## Reducing disadvantage

Location of services and colocation of medical and allied health services is also important to families, with the need to consider those in rural and regional areas and those in low socioeconomic areas at a disadvantage in terms of access. Anecdotal evidence suggests that application of the NDIS in rural and regional areas has led to an increase in private allied health services at the expense of publicly available services. There is a need to ensure that affordable access to paediatric trained allied health is readily available for both diagnosis and ongoing therapy. The siloed, single agency approach to developing the provider market has only further dispersed already scarce allied health resources. It has also diluted capacity to manage quality and credentialing and made the task of coordinating these complex, multi-disciplinary services even more difficult.

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<sup>9</sup> [Bower C, Watkins RE, Mutch RC, et al. Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. \*BMJ Open\* 2018;8:e019605. doi:10.1136/bmjopen-2017-019605](https://doi.org/10.1136/bmjopen-2017-019605) accessed 3 November 2019 3pm

## Standards and Outcomes

During the development of the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia, the NBPSA stressed that any assessment of autism concerns must be undertaken within the context of a broader neurodevelopmental, behavioural diagnostic and functional assessment. Further, the Society advocated for clinicians who do assessments to have a clear set of competencies that inform their suitability to do this type of work. While the former recommendation was incorporated into the guidelines, the latter has yet to be addressed.

Families have reported that NDIS planners do not want a doctor's view, preferring to concentrate on what the families say they need. While this input is critical to the process, some families struggle to understand the context of NDB conditions, disability and likely trajectory for their child. The treating clinician can provide information that is critical to a child's development and advice on the potential and timing for escalation and de-escalation of any needed supports.

**NDIA planners also need a transparent set of standards, competencies and frameworks in order to reduce any unwarranted variation and to allow for evaluation of their outcomes.**

Having an expert who has a known set of competencies carry out a functional assessment by getting to know a child and family is likely to be a much more valid and reliable system than using a tool that a non-expert administers to generate a number or a score.