

## **Submission to Senate Community Affairs Committee Inquiry:**

# **Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder**

13 December 2019

### **Introduction**

Thank you for the opportunity to provide a submission in response to the Senate Inquiry on effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD).

The Aboriginal Medical Services Alliance NT (AMSANT) is the advisory body for Aboriginal Community Controlled Health Services (ACCHSs) in the Northern Territory. Our members are located right across the NT from Darwin to the most remote areas and the ACCHSs sector is the largest provider of primary health care to Aboriginal people in the Northern Territory. ACCHSs deliver comprehensive primary health care in an integrated, holistic, culturally secure framework which combines a population health approach with primary health care service delivery; in addition, ACCHSs are also involved in diverse health research activities. AMSANT provides guidance and advocacy on a wide range of research, public health issues, education, workforce, continual quality improvement programs, social and emotional wellbeing, housing and other determinants of health that affect NT Aboriginal people. It has high level collaborations with the NT and Commonwealth Governments on these issues.

This submission builds upon AMSANT's previous submissions to the NT FASD Strategy consultation (July 2018) and to the development of the National FASD Strategy (September 2017). AMSANT also provided a submission to the Royal Commission into the Detention and Protection of Children in the Northern Territory, whereby several recommendations were put forward relating to prevention, screening and assessment of FASD. We note that there have been a number of enquiries, reviews and requests for submissions on FASD over the past several years however limited evidence of action from these submissions.

### **Overview**

AMSANT embraces a social and cultural determinants of health perspective which recognises that health and wellbeing are profoundly affected by a range of interacting economic, social and cultural factors. Accordingly, we advocate for an evidence-based, holistic and community-led approach to alcohol misuse and the resultant issue of FASD in our communities.

As set out in AMSANT's submission to the National FASD Strategy, we advise against an overly narrow focus on FASD prevention, diagnosis and treatment which may restrict the ability to recognise and address the full range of factors which contribute to alcohol misuse, and result in a range of alcohol related conditions, of which FASD is just one.

AMSANT also notes the Productivity Commission Draft Report *Expenditure on Children in the Northern Territory*, which echoes the recommendation of the Royal Commission for a public health

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approach to the provision of children's services whereby the right mix of universal and early intervention services are well coordinated. This requires the NT and Commonwealth governments to agree on a cooperative, collaborative approach underpinned by community-identified needs and priorities through the Children and Families Tripartite Forum (Productivity Commission, 2019). This is an important opportunity for the Northern Territory to better address the needs of children and families in a coordinated, targeted and responsive way.

To summarise:

- Strategies to prevent FASD should be placed within the broader context of a harm minimisation approach to alcohol, and addressing the underlying causes of alcohol misuse.
- Universal screening of children for developmental delay and behavioural problems should be part of childhood surveillance, with only the children who have features suggestive of FASD to undergo a full diagnostic assessment.
- Evidence-based treatment and care for those affected by FASD must consider the broad context of early intervention and treatment for children with developmental delay, as well as evidence-based treatments for individuals with alcohol and substance addiction.
- There is significant need to consider the overlap with the child protection system and the provision of disability services, in addition to treatment and care approaches across education and criminal justice systems.

This submission responds to select terms of reference grouped under the broader themes of:

1. Alcohol in pregnancy
2. Diagnosis and treatment
3. FASD in vulnerable populations, including within Indigenous communities and those accessing support under the NDIS
4. Support for children and families.

## **1. Alcohol in pregnancy**

Terms of reference addressed:

*(a) the level of community awareness of risks of alcohol consumption during pregnancy*

*(b) the adequacy of the health advice provided to women planning a pregnancy, pregnant women and women who are breastfeeding, about the risks of alcohol consumption*

*(c) barriers that may prevent women receiving accurate, timely and culturally/ethnically appropriate information and advice on alcohol and pregnancy*

### *Whole-of-population response to alcohol*

It is AMSANT's position that FASD is best understood as just one particular serious, and preventable, harm caused by alcohol that adds to all of the other harms associated with alcohol misuse, and therefore requires a whole of population response alongside some targeted measures.

Supply reduction measures including increasing the price of alcohol and reducing its availability are the most cost effective ways to reduce consumption and alcohol-related harms across the population.

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We suggest that population-level alcohol management and supply reduction should be a priority to address alcohol in pregnancy, for the following reasons:

- Most of the harm caused by alcohol in pregnancy occurs at the time of conception and in the early weeks of pregnancy. However it is estimated that almost half of all pregnancies in Australia are not planned (Mazza et al, 2012), thereby limiting the possibility for targeted prevention measures.
- Emerging research has indicated that paternal alcohol consumption at the time of conception can also lead to FASD in their offspring (Day et al, 2016).
- Many women who drink heavily before their pregnancy continue to do so during pregnancy (Anderson et al, 2014), highlighting the need for effective interventions prior to pregnancy.
- Parental alcohol misuse is frequently associated with lack of responsive care, stimulation and neglect of children during their critical years (Mustard, 2006), exacerbating existing deficits in development.
- The consumption of alcohol has strong cultural and social dimensions, therefore change is required at these levels in order to illicit behaviour change at the individual level.

It is important that messages about alcohol and pregnancy include partners, family and friends in addition to women of child-bearing age. Such initiatives include:

- Mandatory labelling on alcohol beverages
- Consistent message from health professionals on the impacts of alcohol
- Public health social marketing campaigns.

Given the cultural diversity of the Northern Territory and the substantial variation in English literacy and the stigmatising nature of potential discussions about drinking in pregnancy, AMSANT also strongly supports ACCHSs providing education and community information locally. ACCHSs will be able to undertake initiatives in a culturally safe and effective way which is sensitive to community concerns and language issues. Some of our members are already undertaking this work but funding is limited and short term. ACCHSs should be resourced to undertake this work including through local media and in Aboriginal languages.

It is important that broad-based alcohol management and supply reduction are coupled with treatment programs which support individuals and families to manage and reduce alcohol misuse, including programs targeted at pregnant women. Individually targeted interventions are necessary, but will have limited impact if implemented in the absence of broader supply reduction measures.

#### *Targeted strategies for mothers and families*

Preventing the stigmatisation of children, mothers and families who are affected by FASD should be considered an underlying principle in understanding approaches to prevention, diagnosis and support for FASD. The possibility that prevention and intervention initiatives may exacerbate stigmatisation and reduce help-seeking must be considered and mitigated wherever possible.

With that in mind, AMSANT recommends provision of targeted strategies in the primary health care setting that support women to make choices about their pregnancy that are in the best interest of themselves and their child. These include:

- Brief intervention.
- Referral to Social and Emotional Well Being services (SEWB) within ACCHSs including ongoing therapeutic, cultural and psychosocial support in SEWB/alcohol and other drugs (AOD) services within comprehensive primary health care. This is increasingly available in

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remote areas but is still not resourced according to need. Long term non-stigmatising support is often required which is holistic and culturally responsive.

- Referral to specialist services if needed including withdrawal and residential rehabilitation. Of note, there is limited rehabilitation that can provide for the needs of families and this often limits access. Note that women who require specialist residential or other care will also usually require SEWB/AOD treatment within Aboriginal primary health care.
- Readily available, culturally appropriate family planning for women and their partners.
- Ensuring that Aboriginal Health Practitioners or community workers work with women's health staff.

These strategies targeted at women during pregnancy will have limited impact unless implemented in conjunction with whole-of-population preventative measures, as well as actions across the social determinants.

## **2. Diagnosis and treatment**

Terms of reference addressed:

*(d) provision of diagnostic services in Australia including capacity, training, integration and diagnostic models in current use*

*(e) the prevalence and nature of co-occurring conditions and of misdiagnosis of FASD*

### *Screening and assessment*

All children should be screened for developmental delay and behavioural problems as part of childhood surveillance. Existing, culturally validated screening tools, such as ASQ-TRAK, should be used to identify developmental impairments. Children who have features suggestive of FASD should then be referred across to a paediatrician for further assessment and full diagnostic assessment if deemed necessary.

Multidisciplinary assessment teams, comprising of at least a neurodevelopmental psychologist, an occupational therapist, speech pathologist and a paediatrician, are needed in each major town across the Northern Territory to assess and diagnose children and young people in both town and in surrounding remote communities.

In most cases, ACCHSs will be best placed to lead these assessment teams and services as they already work with vulnerable populations through an Aboriginal workforce that supports families to engage with services. ACCHSs would necessarily work in partnership with government agencies and not-for-profit services in some locations to pool specialist resources and ensure therapeutic pathways across services. Paediatricians and specialist allied health would ideally work within the ACCHSs.

The current Guide to FASD diagnosis is not a suitable population screening tool but a diagnostic instrument for children who are at increased risk of having FASD and is mainly suitable for specialists. The Guide therefore serves an important but practically limiting function, and more clarity around protocols and referral pathways is needed for frontline workers including those working in primary health care settings.

It is important to note that in the context of the Northern Territory, where access to paediatricians and allied health (particularly neuropsychology) is currently limited in some places, it is vital that access to supports and services are not directly linked to a requirement for a FASD diagnosis until

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access to these multidisciplinary teams is made universally available. Paediatric assessment alone is insufficient and other allied health specialists are essential for an effective assessment and diagnostic service. For all children with developmental delay, screening is not ethical unless there are also treatment interventions available. With the introduction of the NDIS, this brings additional resources to the disability sector and so population screening in areas with little current resources needs to be increased so that children can be formally diagnosed.

In Central Australia, where there is an identified high prevalence of developmentally vulnerable Aboriginal children, the Central Australian Aboriginal Congress initiated the Child and Youth Assessment and Treatment Service (CYATS) in 2018. The service partners with providers across health agencies and across other Congress child and family services, and works closely with families. Demand for the service is high and the waitlist for assessment is long. Despite being the only service of its kind in Central Australia, funding has been drawn from different sources and the future of the service is uncertain. Though the precise number is unclear, there is a significant cohort of children and young people who are missing out on accessing supports through the NDIS because of the limited capacity to receive an appropriate assessment and diagnosis. This issue would be even more pronounced in other parts of the NT where assessment services are not available. AMSANT therefore requests government support and enhancement of CYATS and development of similar regional child and youth assessment services.

#### *Addressing multiple causal factors of developmental delay*

It is important to be clear that there are multiple other contributors to vulnerability in children including adverse social circumstances, physical health problems affecting development including anaemia and recurrent infections, and suboptimal parenting which may be due to a range of issues and exposure to traumatic events in the early years including family violence. Often, more than one underlying causal factor will be found. There needs to be a holistic screening and further assessment process which should not usually require primary health care staff to make a diagnosis of FASD.

There is also an established similarity in symptoms arising from traumatic childhood experiences, such as maltreatment, as those caused by prenatal alcohol exposure (Norman et al, 2012, Rutter 1998, cited by Price et al, 2017). Permanent damage to the brain can be caused both by prenatal alcohol exposure and trauma, which may lead to deficits in cognitive, social and behavioural domains (Price et al, 2017).

AMSANT advocates for a social and emotional wellbeing (SEWB) framework in understanding and addressing complex health, mental health and substance abuse issues, including alcohol and other drugs (AOD) and FASD. Such a framework is underpinned by principles of culturally responsive, trauma-informed care and encompasses domains of connection to culture, body, mind and emotions, land, family and kinship, spirituality and community (Gee et al, 2014). Understanding the implications of disruption and connection in relation to these domains is central to developing the capacity of staff, services and organisations to create a culturally informed environment in which healing and wellbeing can be nurtured.

#### *Treatment and care*

Treatment and care interventions related to FASD must be considered for both the FASD affected child, and the parents who are engaged in harmful alcohol use.

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While it is accepted that there is no 'cure' for FASD, treatment and care strategies must focus on the fact that a person with FASD can be assisted by programs to help them with their learning and behaviour.

Early childhood intervention programs will be central to improving these outcomes and should be provided across three tiers: universal (available to all families), targeted (available to higher risk groups within the population, e.g. younger parents), and indicated (for children/families with specific needs, e.g. developmental delay or children in the child protection system).

Population level interventions for all disadvantaged children are better able to capture the wide ranging damage that is being done to young children due to alcohol abuse, even when this may not be diagnosed as FASD. Reducing harmful alcohol use among parents of FASD affected children will require primarily the consideration of price and availability factors to reduce supply across the entire population. Additionally, it is important that people who misuse alcohol have ready access to alcohol treatment programs which offer medical, psychological and social/cultural supports.

These treatment options should be available as residential programs in urban settings, as well as community-based programs provided through Aboriginal community controlled organisations. Given the current dearth of services like this available in the Northern Territory, this will require significant additional investments in infrastructure and training, in order to meet demand.

An important consideration for these kinds of programs is the need for transitional accommodation and services to assist clients in addressing the social factors (lack of housing/overcrowding, debt, family breakdown etc) that frequently contribute to drinking behaviours, and which will often lead to relapse if they are not addressed.

Children with developmental or behavioural issues need access to both paediatricians but also specialist allied health staff, as already noted, for both diagnosis and ongoing specialist treatment. Existing programs such as parent support and intensive family support programs need to be available to families who need additional support but should be for all families who need them – not just for those with diagnosed FASD or developmental delay. The NDIS should help to build an Aboriginal workforce in disability and this should include a childhood/family support workforce that has training in early childhood and disability.

### **3. FASD in vulnerable populations, including within Indigenous communities, people in the criminal justice system and those accessing support under the NDIS**

Terms of reference addressed:

*(h) the prevalence of, and approaches to, FASD in vulnerable populations, including children in foster and state care, migrant communities and Indigenous communities*

*(j) the social and economic costs of FASD in Australia, including health, education, welfare and criminal justice*

*(k) access, availability and adequacy of FASD support available through the National Disability Insurance Scheme, including access to effective and early intervention services for individuals diagnosed with FASD*

#### **Aboriginal children**

While there are no reliable figures on the prevalence of FASD in Australia, it has been suggested

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based on the data that is available that rates are higher in Indigenous communities (AIHW & AIFS 2014). Within the Northern Territory it is likely that a significant number of Aboriginal children and families are affected by FASD due to the high prevalence of alcohol related harms experienced by this group. Indigenous people are 1.3 times more likely to abstain from alcohol than non-Indigenous people. However, of the Indigenous people that do drink, they are more likely to drink at harmful levels (Gray et al, 2018). Some 30 per cent of Indigenous adults in the Northern Territory report drinking alcohol at risky or high risk level, and one in eight women report alcohol consumption at their first antenatal visit (NTG, 2010).

Data from the Australian Early Development Census (AEDC) also indicate the high prevalence of developmental vulnerability in children across the Northern Territory, with 36 per cent of children developmentally vulnerable in one or more domains and 23 per cent across two or more domains (AEDC, 2018). Furthermore, national ABS data from 2012 identified that Aboriginal and Torres Strait Islander children aged 0-14 years were more than twice as likely as non-Indigenous children to have a disability (15.2 per cent compared with 6.6. per cent).

While some of this disability will be due to undiagnosed FASD, much of it is also the direct result of early childhood disadvantage which is causally related. Key factors underlying this disadvantage include unemployment, overcrowded and poor quality housing, alcohol abuse and mental health problems, and resultant child neglect. This reinforces the need for an approach that has a focus on Aboriginal communities, which does not stigmatise, and simultaneously encompasses addressing the social determinants of health.

Furthermore, it is imperative to also consider the high incidence of other alcohol related conditions and the reality that FASD is just one aspect of a complexly determined set of neurodevelopmental impairments which result from multiple factors.

Programs to prevent, assess, diagnose and manage FASD in Aboriginal populations should be led by Aboriginal community controlled health organisations. Prominent examples of such programs include the neurodevelopmental clinic operating at Central Australian Aboriginal Congress (CAAC) (CYATS, referred to above under section 2) and the planned clinic at Danila Dilba. However, the demand for services is such that these services must be increased and expanded to all urban ACCHSs.

*Young people in contact with the child protection and criminal justice systems*

AMSANT notes and endorses the submission to this inquiry by the Northern Australian Aboriginal Justice Agency (NAAJA) which addresses this topic in more detail.

All young people who come into contact with the youth justice system should have access to a neurodevelopmental assessment including for FASD and these should be conducted in a systematic way.

This was highlighted by the Royal Commission into the Detention and Protection of Children in the Northern Territory, which found that FASD screening of detainees was not undertaken, despite the likelihood that a significant number of detainees would be affected by FASD (Commonwealth, 2017). The Royal Commission recommended at 15.1, part 3(b) that:

*The comprehensive medical and health assessment required to be carried out [on admission of a young person or child to a detention centre], should include ... a behavioural questionnaire to determine whether a formal assessment for Fetal Alcohol Spectrum Disorder*

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*should be conducted, and if so determined and if the detainee has not previously been the subject of a formal assessment, that assessment to be conducted. (Commonwealth, 2017)*

A recent study revealed 89 per cent of young people in Banksia Detention Centre in Western Australia has a severe neurodevelopmental condition (Bower et al, 2018). These conditions may have a significant impact on sentencing and receiving the right care, however currently in the Northern Territory, assessment can be difficult to access and is usually dependent on strong advocacy from the legal representatives for the child.

#### *NDIS*

The rollout of the NDIS, and the Early Childhood Early Intervention (ECEI) approach particularly, provides an opportunity to enhance primary prevention and early detection of disabilities such as FASD. Due to an inability to access treatment and supports for people with disability an ethical disincentive has previously existed for health professionals to make a FASD diagnosis. Under the NDIS however there is a unique opportunity to address issues of early childhood development and disability in remote Aboriginal communities through the direct commissioning of funds to existing health service providers, including ACCHSs where available, to expand the intervention, treatment and support options for eligible clients in these areas.

AMSANT has documented concerns regarding the competitive, market-based NDIS and that many aspects of Aboriginal health and the wider human service delivery sector are not suited to the model of service delivery under the NDIS system. The model of comprehensive, holistic and culturally responsive care provided through the Aboriginal community controlled primary health care model cannot be replicated through a privatised or government system. Further, the remote locations in which our member ACCHSs operate lack sufficient economies of scale to support the viable provision of the full range of health and human services necessary for the NDIS, let alone multiple, competitive providers of services (AMSANT, 2019).

AMSANT advocates for a centralised, needs-based planning approach taken to the delivery of NDIS services to Aboriginal people in the NT, similar to that established by the NT Aboriginal Health Forum (NTAHF). Such a forum would allow for centralised funds pooling, planning and needs-based allocation of NDIS funds for Aboriginal people with a disability, including FASD.

#### **4. Support for children and families**

Terms of reference addressed:

*(I) support for adults with FASD and for parents and carers of children with FASD*

While it is accepted that there is no 'cure' for FASD, treatment and care strategies must focus on the fact that a person with FASD can be assisted by programs to help them with their learning and behaviour. In addition, the disability from FASD can be compounded by cognitive damage due to exposure to neglect (more likely if parents are drinking), adverse life events, poor nutrition and anaemia. These are all amenable to early intervention through SEWB support for parents, family support programs, and excellent clinical primary health care. Importantly, poor nutrition and poverty need to be addressed through societal changes as well.

Early intervention, and specifically intervention in early childhood, is the most cost-effective intervention to break cycles of intergenerational disadvantage and trauma and improve long-term outcomes across a range of health and wellbeing measures.



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Population level interventions for all disadvantaged children are better able to capture the wide ranging damage that is being done to young children due to alcohol abuse and other associated factors, even when this may not be diagnosed as FASD.

ACCHSs bring with them strong relationships with communities, understanding community needs, cultural competence, and a permanent presence in Aboriginal communities. This makes them well-placed to deliver primary prevention and early intervention services that are foundational in the reduction of alcohol-related harms, including FASD, in our communities.

ACCHSs provide a model of comprehensive primary health care which incorporates early childhood programs, family support, mental health interventions incorporating social and emotional wellbeing (SEWB) and alcohol and other drug (AOD) services, and prevention and health promotion programs.

Furthermore, the child health and early childhood development core services model developed through the NT Aboriginal Health Forum provides a clear blueprint for the services needed to support vulnerable families, including those with FASD, and must be fully implemented. This model identifies the need for universal, indicated and targeted measures to be provided across the following services: quality antenatal and postnatal care, nurse home visitation, parenting programs, intensive child development programs, and two years' preschool (NTAHF, 2016).

Examples of effective early childhood intervention programs being used in the Northern Territory include:

- The Nurse Family Partnership Program: Adapted by the Central Australian Aboriginal Congress (CAAC) for use in an Indigenous context, is a preventative outreach program which works with families to develop relationships and access services, in order to optimise healthy childhood development. Home visitation programs like this one have been found effective in reducing the use of alcohol and other substances for those children in their young adult life (Olds et al, 1997).
- The Abecedarian Educational Day Care program: Also successfully adapted and utilised by CAAC in the Northern Territory. This program has children attend a day care centre on a daily basis with a focus on providing access to enriched care from infancy to five years. Evaluations of this program from the US have found that treated individuals had acquired higher levels of education, were less likely to be teen parents, and less likely to report symptoms of depression (Campbell et al, 2012).

In order for the sector to improve health outcomes in this important area, including for children with FASD and other kinds of developmental delay, additional funding is required to ensure the full suite of services is made accessible through health services in all communities throughout the Northern Territory.

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