

# Addressing Fetal Alcohol Spectrum Disorder (FASD)

in the Northern Territory  
2018-2024





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# Minister's Foreword

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong condition which is entirely preventable, by not consuming alcohol during pregnancy. As acknowledged in the Alcohol Policies and Legislation Review Final Report, the greatest gains to be achieved are through prevention.

There are many factors that can contribute to the development of a healthy child, but we also know that alcohol can cause harm to a developing baby, and it does not discriminate. To give our children the absolute very best start to life, we must look at ways to ensure that this message is spread far and wide to the entire population, so that families and communities can support each other and work together to ensure our children – our future leaders and elders – are not born with preventable disabilities such as FASD.

The Territory Government is delivering broad alcohol reforms that aim to reduce the demand, supply and harm caused by alcohol across the NT. It is anticipated that the initiatives targeting alcohol misuse across the NT will reduce population levels of consumption, which will have a flow on effect and contribute to reducing the incidence of FASD in our community.

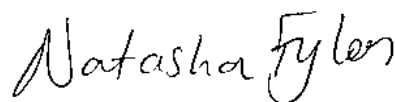
The NT FASD Strategy also brings a strong focus to improving assessment and support. The aim is to improve the capacity of services to recognise any neurodevelopmental delay, and respond accordingly. This will be achieved through awareness raising, education of frontline and community based staff, and increasing parenting skills development. Specialist assessment clinics

will ensure that multidisciplinary services can be coordinated effectively and wrap around care is mobilised as quickly as possible, when needed, regardless of whether a diagnosis is made.

The reality is that many people in our community are impacted by FASD and experience the negative effects of living with FASD, and are doing so without support. We will provide education to specific workforces such as public housing officers, the judiciary, and custodial officers so that FASD will be considered and acknowledged in any interactions, and that support services are offered where appropriate.

The Territory Government through the Alcohol Harm Minimisation Working Group will monitor the actions arising out of the NT FASD Strategy and work to increase care coordination and provide an integrated response to addressing FASD. The Territory Government will work in partnership with the NT Primary Health Network and Aboriginal Community Controlled Health Services to educate individuals to prevent FASD as well as assess and provide support to those already impacted by FASD.

I am pleased to present the Northern Territory Fetal Alcohol Spectrum Disorder Strategy to support all Territorians having the best start in life.



**Minister for Health**  
**the Honourable Natasha Fyles MLA**

# 01

## Guiding principles for our approach

- » increase community knowledge and understanding about FASD through a Whole of Government approach
- » this lifelong disability is entirely preventable – this is where our main efforts must be focused
- » promote positive health messages to increase health enhancing behaviour amongst child bearing population to avoid alcohol during pregnancy
- » encourage collaboration and the creation of local network groups and partnerships to assist with achieving and monitoring our collective response
- » primary care providers have a key role to play across the NT
- » Aboriginal Medical Services and Aboriginal Community Controlled Health Services have a key role to play in driving change in Aboriginal Communities
- » recognise the barriers to assessment and referral to support services (such as stigma)
- » build the capacity and health literacy of families and communities to recognise and respond to FASD.

### **The National Fetal Alcohol Spectrum Disorders Strategic Action Plan 2018-2028.**

**Priority actions of the national plan include:**

- 1. Prevention**
- 2. Screening and diagnosis**
- 3. Support and management**
- 4. Populations at increased risk**

**The Territory Government has aligned this strategy to address FASD in the NT with similar key action areas.**

# A quick glance

Key actions for the NT are as follows:

## **A focus on prevention of FASD by:**

- » continuing to maximise public awareness and increase health literacy of the risks of consuming alcohol during pregnancy
- » ensuring our health and human services workforce are aware of their roles in preventing FASD and provide the same clear and consistent key messages
- » ensuring that adolescents and women of childbearing age, and their partners, have adequate access to sexual health information, reliable and affordable contraceptives, and pregnancy support services
- » ensuring that treatment for alcohol misuse is available and accessible to all women and that women who are high risk alcohol users are being referred to treatment providers, including through proactive outreach methods
- » ensuring that wrap around services are mobilised to understand the risk factors, and address the social determinants of health for women who are high risk alcohol users
- » strengthening models to attract and support pregnant women in treatment services and providing follow up and after care services following periods of residential treatment
- » continuing to support programs that build healthy and strong families and providing parenting advice and support to new parents.

## **A focus on assessment of children for neurodevelopmental disorders by:**

- » improving the ability of families and communities to recognise and respond to neurodevelopmental impairment
- » increasing early intervention and the number of children assessed by a multidisciplinary team for neurodevelopmental disorders early in life
- » upskilling workers in Aboriginal Community Controlled Health Services in targeted regions to coordinate awareness raising and community responses to FASD
- » improving communication between teams who may be involved in the assessment of children at risk of FASD.

**Efforts to improve management and support for individuals and families impacted by FASD by:**

- » continuing to support programs that offer services and education to families, schools and carers who are impacted by FASD
- » continuing to transition existing clients on to the National Disability Insurance Scheme (NDIS)
- » ensuring that children with support needs are connected with support services early in life
- » ensuring that families receive assistance when applying for the NDIS.

**A focus on priority groups which include:**

- » targeting education and brief interventions towards adolescents and women of childbearing age and their support networks
- » targeted assessment of youth in juvenile justice settings
- » facilitating assessment of children in out of home care.

# 02

## What do we know about FASD and why is it a problem?

The consumption of alcohol during pregnancy can result in a range of neurodevelopmental impairments. FASD is the diagnostic term used to describe the spectrum of physical, cognitive, behavioural and neurodevelopmental abnormalities that can be caused by maternal consumption of alcohol during pregnancy.

The National Health and Medical Research Council's *Australian Guidelines to Reduce Health Risks from Drinking Alcohol* advise that when pregnant or planning a pregnancy, not drinking alcohol is the safest option<sup>1</sup>.

FASD is a preventable disability, by avoiding alcohol during pregnancy. FASD is causing harm to children and placing burden on families, carers and communities world wide and in Australia. Feedback from health professionals, educators and communities indicates that there appears to be a high incidence of FASD in the NT.

Antenatal exposure to alcohol can result in significant adverse health, social and legal outcomes for a child as well as their families and the communities that support them. The effects of FASD vary in type and degree, and physical effects such as growth retardation, certain facial features, and birth defects such as cardiac, skeletal, or renal abnormalities and sensory impairment may be seen. Other effects include neuropsychological and

behavioural issues resulting from diminished intellectual, adaptive and executive function, deficits in learning, memory, visual-spatial ability, language, motor function, and attention. These effects can result in disabilities that require life long support and can prevent independent living. Resultant behavioural problems can also pose risks to individuals and the community due to an inability of the FASD individual to understand and learn, and not be responsive to punitive measures.

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Diagnosis of FASD involves assessment of an individual by a multidisciplinary team of clinicians and trained health professionals. The individual is assessed for neurodevelopmental impairments as well as for general physical and developmental abnormalities.

Depending on the age of the child, this assessment may be longitudinal, as not all neurodevelopmental domains can be assessed in early childhood.

*The Australian Guide to the Diagnosis of FASD*<sup>2</sup> is designed to guide and assist clinicians in the

1 National Health and Medical Research Council (2009), *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*, [https://www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/ds10-alcohol.pdf](https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/ds10-alcohol.pdf)

2 Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report to the Australian Government Department of Health (2016), *Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)*, [https://www.fasdhub.org.au/siteassets/pdfs/australian-guide-to-diagnosis-of-fasd\\_all-appendices.pdf](https://www.fasdhub.org.au/siteassets/pdfs/australian-guide-to-diagnosis-of-fasd_all-appendices.pdf)



diagnosis, referral and management of FASD. The NT is continuing to develop its processes to support the diagnosis of FASD.

FASD is a lifelong condition with no cure. The central nervous system damage which the child is born with is irreversible and permanent, and current treatment options are predominantly supportive. However, cognitive development can be enhanced and support services can improve the quality of life for those affected.

In the NT, there were 4014 babies born in 2016<sup>3</sup>. FASD prevalence in the NT is unknown, and there are no national estimates of the prevalence of FASD in Australia<sup>4</sup>. Anecdotally, we know that many NT children are experiencing learning difficulties, have difficulty controlling their emotions and impulses, and many of our young people are coming into contact with the juvenile justice system.

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3 Li L, O'Neil L. *Mothers and Babies 2016: Northern Territory Midwives' Collection*. Department of Health, Darwin, 2019 (to be published)

4 Burns L, Breen C, Bower C, O' Leary C, Elliott EJ. *Counting fetal alcohol spectrum disorders in Australia: the evidence and the challenges*. *Drug Alcohol Rev* 2013;32:461-467

A recent study conducted in a youth detention centre in Western Australia suggests that as many as 36% of the young people in the youth detention centre had FASD<sup>5</sup>.

5 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

# 03

## Whole of Government approach

The social determinants of health must be a consideration of our approach. There are many reasons why Territorians misuse alcohol, including trauma (including trauma experienced as a result of domestic, family and sexual violence and/or sexual abuse), homelessness, family dysfunction, social and peer pressure, stress, addiction and mental health issues.

A Whole of Government approach to addressing FASD includes interventions to address all of these key areas and aims to streamline the coordination of initiatives, strengthen existing activities, and increase efforts to address the gaps in services.

The Territory Government has a range of activities and initiatives currently occurring which aim to directly or indirectly reduce the incidence and impacts of FASD through addressing the social determinants of health.

As outlined in the Early Childhood Development in the Territory 2018-2028 *Starting Early for a Better Future* plan, an investment by the Territory Government of \$35.6 million over four years will be part of a coordinated effort to structure the approach to health, early learning, family support services, and child protection across the Northern Territory<sup>6</sup>.

Broad alcohol harm minimisation initiatives that aim to reduce demand, supply, and harm are aimed to reduce the drinking levels across the population and therefore assist with decreasing the risk of women consuming alcohol during pregnancy resulting in reduced rates of FASD.

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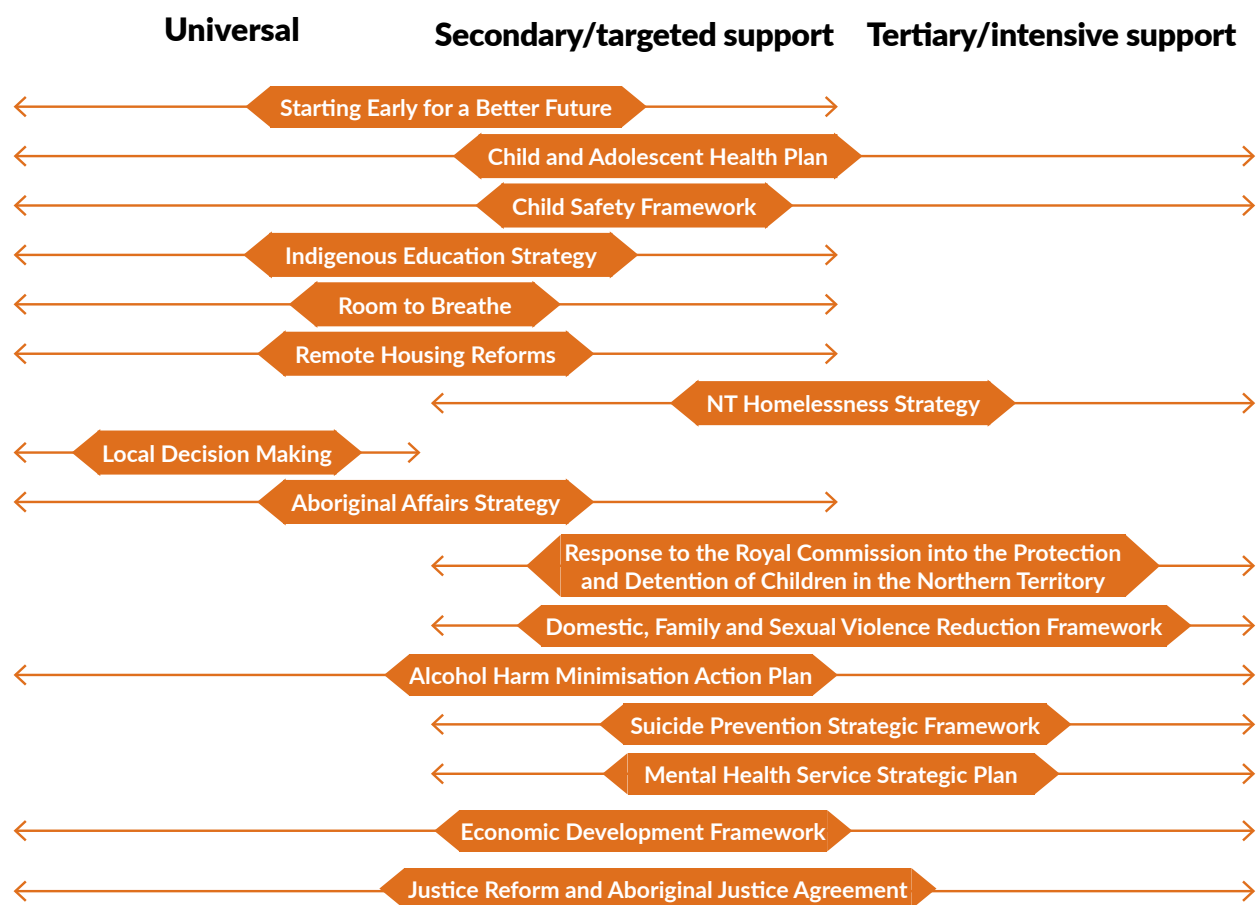
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The Territory Government, through its *Alcohol Harm Minimisation Action Plan 2018-2019*, has committed to a variety of actions to address four key areas:

- » strengthen community response
- » effective liquor regulation
- » research, data and evaluation
- » comprehensive, collaborative and coordinated approach by government.

<sup>6</sup> Northern Territory Government (2018) *Starting Early for a Better Future - Early Childhood Development in the Northern Territory 2018-2028*, [https://earlychildhood.nt.gov.au/\\_data/assets/pdf\\_file/0003/450885/starting-early-for-a-better-future-plan.pdf](https://earlychildhood.nt.gov.au/_data/assets/pdf_file/0003/450885/starting-early-for-a-better-future-plan.pdf)

## Key Strategic Plans and Priorities



6 Northern Territory Government (2018) *Starting Early for a Better Future – Early Childhood Development in the Northern Territory 2018-2028*, [https://earlychildhood.nt.gov.au/\\_data/assets/pdf\\_file/0003/450885/starting-early-for-a-better-future-plan.pdf](https://earlychildhood.nt.gov.au/_data/assets/pdf_file/0003/450885/starting-early-for-a-better-future-plan.pdf)

# 04

## Prevention

Given that FASD is entirely preventable, it makes sense that the majority of efforts are focused on prevention. However, the approach must be carefully considered to ensure that the burden is not entirely placed on women.

We must consider the issues that stigma may cause, which could hinder a person's willingness to be truthful about, and seek treatment for, their alcohol use during pregnancy. Our approach to prevention needs to be nurturing and without judgement, and aimed at the whole of the population, including men. It also needs to include people from diverse backgrounds, cultures, and socio-economic status.

The Four-Part Model of Prevention<sup>7</sup> implemented by the Public Health Agency of Canada outlines the four levels of prevention where efforts need to be targeted. Broad awareness building and health promotion activities form the *first level of prevention*, which is much more complex than simply providing information on the risks of alcohol use during pregnancy.

A systematic whole of community level approach is required and involves engaging a wide range of people throughout the community who have an important role to play in ensuring alcohol is not consumed during pregnancy.

<sup>7</sup> Public Health Agency of Canada (2008), *Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives*, <http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/publications/cp-pc/pdf/cp-pc-eng.pdf>

The alcohol industry has a responsibility and role to play through providing information to consumers about the harms caused by alcohol consumption during pregnancy. Some alcohol products currently display a warning about the harmful effects of alcohol during pregnancy however product labelling is currently voluntary.

Alcohol is treated as a food under the Australian and New Zealand Food Standards legislation and is subject to the food standards set by the independent statutory agency Food Standards Australia New Zealand under the Food Standards Australia New Zealand Act 1991.

The Australia and New Zealand Ministerial Forum on Food Regulation recently reviewed the evidence and agreed that mandatory labelling standards for pregnancy warning labels on alcohol products should be developed. They have requested Food Standards Australia New Zealand develop this mandatory labelling standard as a matter of priority, and asked that they include a pictogram and relevant warning statement.

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There are a range of resources that the Australian Hotels Association NT (AHA NT) can distribute for display in takeaway alcohol outlets to raise awareness of the harms associated with alcohol consumption during pregnancy and NT Health will work with the AHA NT to ensure that message is clear and consistent.

Campaigns that target men, families, health and human services workforces, to encourage a change in the current drinking culture, are also imperative. Broad awareness raising campaigns across the entire community are needed and the messaging must be clarified so that it is clear and consistent throughout all resources, education and campaigns. There is a variety of resources currently available on the FASD Hub ([www.fasdhub.org.au](http://www.fasdhub.org.au)) and through the National Organisation for Fetal Alcohol Spectrum Disorders (NOFASD) Australia website ([www.nofasd.org.au](http://www.nofasd.org.au)), as well as NT-specific tools such as the 'Yarning about Alcohol Use in Pregnancy' and Advice Card developed by the Remote Alcohol and Other Drugs Workforce Program in collaboration with Menzies School of Health Research's Aboriginal and Islander Mental Health Initiative NT.

Further promotion of these throughout the wider community, as well as within specific workforces through newsletters and internal memorandums, will be key to raising awareness. Some resources may require modification to suit remote contexts and the Territory Government will investigate pictorial formats, such as talking books or producing resources in a variety of different languages to ensure key messages are received.

### **New Territory Government initiatives to increase community knowledge about FASD**

The Territory Government will continue maximising public awareness to further educate the community on the lifelong impacts of FASD caused by antenatal alcohol exposure through broad social media and health promotion campaigns. This will be done in collaboration with Aboriginal Community Controlled Health Services.

The Territory Government will ensure that all health and human services staff are aware of their role in health promotion and prevention of FASD, and that the messaging about consuming alcohol during pregnancy is clear and consistent and provided at any opportunity.

The *second level of prevention* focuses on adolescent females and women of childbearing age. It involves ensuring there are opportunities to have discussions with healthcare providers and their support networks about what it means to have a healthy pregnancy, and the risks associated with alcohol use during pregnancy. This key message is incorporated into the Young Women's Community Health Education Program, which can be delivered by midwives, Aboriginal Health Promotion Officers and Aboriginal Health Workers. NT Health will update its 'Healthy Pregnancy Healthy Baby' pregnancy book for Aboriginal and Torres Strait Islander women of the Northern Territory, to include information on FASD and its impacts.

According to the National Health and Medical Research Centre's *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*<sup>8</sup>, the risk of alcohol-related injury increases with the amount of alcohol that is consumed on a single occasion. For healthy men and women, drinking no more than four standard drinks on a single occasion reduces the risk of alcohol-related injury arising from that occasion. It is also recommended that for healthy men and women, drinking no more than two standard drinks on any day reduce the lifetime risk of harm from alcohol-related disease or injury.

For a woman who is pregnant or planning a pregnancy, the guidelines recommend that not drinking is the safest option. Given that approximately 50%<sup>9</sup> of pregnancies in Australia are unplanned, many women will consume alcohol before knowing they are pregnant. Adolescents (both male and female) and women of childbearing age are therefore a priority group the Territory Government will focus its prevention activities towards.

There are limitations to the self-report data which is currently collected relating to alcohol consumption during pregnancy. NT Health will ensure that primary health care providers, at every initial contact with an adolescent or woman of

childbearing age, use the Alcohol Use Disorders Identification Test – Consumption (AUDIT-C) tool. NT Health will support primary health care providers to build confidence in having conversations about alcohol use during pregnancy with all adolescents or women of childbearing age through provision of further training.

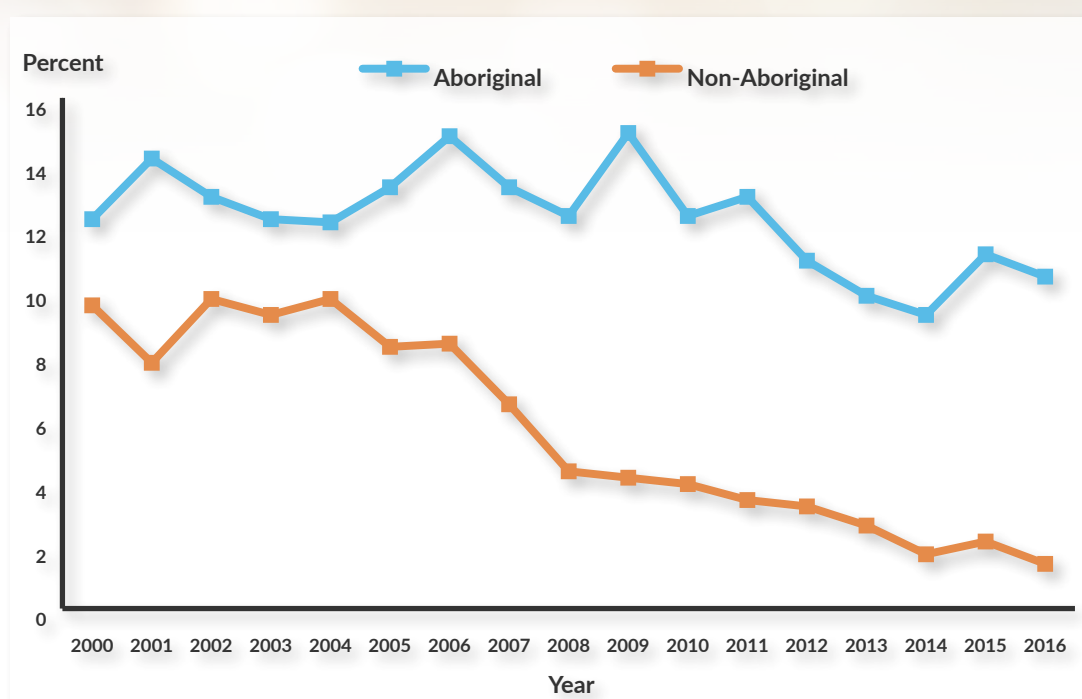
Data relating to the use of the AUDIT-C tool will assist with future reporting and analysis of alcohol consumption during pregnancy. Brief intervention activities that highlight the potential impact of alcohol consumption during pregnancy will also be a priority.

All adolescents and women of childbearing age must be made aware of the potential risks associated with their alcohol consumption including the permanent damage that can be caused to an unborn child even when alcohol consumption during pregnancy is inadvertent before the pregnancy is confirmed. Sexual health and alcohol and other drug education programs will include FASD as a potential risk of unplanned pregnancy and NT Health will work towards increasing access to reliable and affordable Long Acting Reversible Contraceptives, particularly for adolescents, by increasing the number of health professionals trained in the insertion of contraceptive implants.

8 National Health and Medical Research Council (2009), *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*, available at: [https://www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/ds10-alcohol.pdf](https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/ds10-alcohol.pdf)

9 Marie Stopes International (2008), *Real Choices: Women, contraception and unplanned pregnancy*, <https://www.mariestopes.org.au/wp-content/uploads/Real-Choices-Key-Findings.pdf>

## The percentage of self-reported alcohol consumption during pregnancy for NT mothers



### Note:

1. Only NT residents who gave birth in the NT were included.
2. The percentage of NT mothers reported drinking alcohol during their first antenatal visit and around 36 weeks' gestation in the graph was calculated using the AIHW default position: any yes as yes, both no or no and unknown as no, then both unknown as unknown.
3. Although the collection of this indicator has improved in recent years, the proportion of missing data remains sizeable. Missing data for alcohol consumption was more prevalent among the antenatal records of Aboriginal mothers than non-Aboriginal mothers.
4. The data used are limited to health information available at the time of data entry. In instances where an antenatal record is incomplete or missing, the midwife entering information into the Birthing Suite Module of CareSys or the NT Midwives' Collection website is limited to the details at hand. Key antenatal indicators such as visit dates and health behaviours are the most likely to be affected as this information is only recorded on antenatal records.

## New Territory Government initiatives targeting all adolescents and women of childbearing age

The Territory Government will further train health professionals and other workforces where women may seek support (juvenile justice, probation workers, police officers, detention workers, staff in correctional facilities, shelter homes, mental health facilities, foster carers, teachers, and staff at schools) about FASD and its impacts, using experiential styles of learning informed by trauma informed principles.

The Territory Government will focus on prevention activities that target all adolescents including raising awareness amongst young people and people who are sexually active through drug education in schools, the Alcohol and Other Drug Youth Grants Program and community driven projects that develop local solutions and practical actions through funding of Alcohol Action Initiatives. This will include information on the importance of antenatal care commencing in the first trimester of pregnancy.

The *third level of prevention* will target women to ensure that treatment for alcohol misuse is available and accessible. This is not only for pregnant women, but is also for all adolescent females and women of childbearing age who may experience problems associated with alcohol consumption that require treatment.

The Territory Government currently funds a range of alcohol and other drug treatment services. Thirty-three percent of episodes of treatment for alcohol use during 2016/17 were for women<sup>10</sup>. We know there are many barriers that women face when seeking treatment for alcohol and/or drug issues. These may include family or child caring responsibilities, fear of losing custody of their children, trauma, fear of associated stigma, shame, financial issues, and/or lack of encouragement and support.

NT Health will focus on treatment for alcohol use through referral from a range of services including Sobering Up Shelters, General Practitioners, and other health care professionals.

Proactive outreach methods will ensure women at risk are connected to appropriate treatment services.

NT Health will focus on improved coordinated care that focuses on improving the social determinants of health for all women identified pre-pregnancy, as well as during pregnancy, as high-risk alcohol users.

NT Health will continue to explore residential treatment and hostel models for women in the antenatal and postnatal period.

Significant funding has been made by the National

<sup>10</sup> Australian Institute of Health and Welfare (2018), Alcohol and other drug treatment services in Australia 2016–17 - supplementary tables – States and Territories (clients), available at <https://www.aihw.gov.au/reports/alcohol-other-drug-treatment-services/aodts-2016-17/data#page1>



Health and Medical Research Council (NHMRC) to establish the FASD Research Australia Centre of Research Excellence. NT Health will continue to monitor research on FASD, including the use of biomarkers to screen for alcohol use in pregnancy.

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### Proactive outreach methods will ensure women at risk are connected to appropriate treatment services.

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#### New Territory Government initiatives to provide treatment for pregnant women

NT Health will strengthen models of care to attract and support pregnant women in treatment services for longer and to encourage women to receive antenatal care within the first trimester of pregnancy.

The *fourth level of prevention* is about supporting new mothers once the baby is born, to maintain healthy lifestyle changes to build stronger families and resilience.

Women who receive treatment will receive follow up and after care services following any periods of residential treatment. This is particularly important for women who receive treatment for alcohol use during pregnancy.

The Families as First Teachers program is an early learning and family support program, currently in both remote communities and urban areas, which aims to improve the developmental outcomes

of children. Supporting families to learn through quality child-centred learning experiences and increasing health literacy regarding nutrition, health and hygiene are key components of this program.

Targeting families and their children prior to the child starting school, the program can identify any areas where additional support services are needed, and provide the crucial link to these services.

The Early Childhood Development in the NT 2018-2028 'Starting Early for a Better Future' plan outlines Territory Government's commitment to fund early learning and family support programs at Families as First Teachers sites and is an investment of \$10.7 million annually.

The Australian Government Department of Health funds two programs under the Indigenous Australians' Health Programme that aim to improve child and maternal health. The Australian Nurse Family Partnership Program offers support to new mothers following the birth of a baby. This program has a particular focus on maternal health and early childhood development and aims to improve prenatal health, provide assistance with learning parenting skills and help families with planning future pregnancies and completing education or commencing employment following the birth of a baby and in the child's first two years of life.

The second Australian Government funded program is the New Directions: Mothers and Babies Services program. Services across selected remote, rural, regional, and urban sites provide Aboriginal and Torres Strait Islander families that have young children access to support, information, education, and advice about antenatal and baby care, parenting and childhood development. Through this program, developmental milestones are monitored, and health checks are undertaken prior to the child commencing school.

The Territory Government has invested \$8 million over three years to work with the Aboriginal Community Controlled Health Service sector to implement sustained nurse-led home-visiting. This will include introducing the Maternal Early Childhood Sustained Home-visiting (MECSH) program into the NT. MECSH is a structured program of nurse home visits which aims to improve transition to parenting, improve child health and development, and improve child life outcomes.

The Healthy Under 5 Kids – Partnering Families program is a universal health screening initiative being implemented by the Territory Government. The program is for families with 0-5 year olds and aims to standardise care across the NT, with a major focus on improving child health and wellbeing outcomes for this cohort through systematised and timely assessment/reporting and referral as required.

The program builds on partnerships between the family and their health professional in urban and remote Territory Government health centres, aiming to empower families to become more confident with parenting through provision of anticipatory guidance, information and support. As part of the *Starting Early for a Better Future* plan, the Territory Government has recently announced additional funding to expand this program to additional locations throughout the NT.

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### The Healthy Under 5 Kids – Partnering Families program is a universal health screening initiative being implemented by the Territory Government.

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An education package has been developed by the NT Department of Health in conjunction with Charles Darwin University and aims to provide remote area health providers with the knowledge and skills on childhood development, and assessment to incorporate the Healthy Under 5 Kids – Partnering Families into service delivery.

The Healthy School Age Kids program is a joint program between NT Health and the NT Department of Education providing health screening for school-aged children in remote communities, and supporting early intervention, health promotion, and integrating other relevant programs and services enhancing care coordination.

# 05

## Assessment

Currently, a diagnosis of FASD is a lengthy process that can be costly for individuals and requires attendance at multiple appointments. In order to get a diagnosis of FASD, the child must receive an assessment by a paediatrician and multiple assessments by a range of allied health professionals. Depending on the age of the child, this assessment may be longitudinal, as not all neurodevelopmental domains can be assessed in early childhood. Concurrently as the diagnosis process is occurring, if support needs are identified the priority is to get the child connected with support services regardless of whether a diagnosis is eventually made.

### **National Disability Insurance Scheme – Early Childhood Early Intervention funding**

The National Disability Insurance Agency (NDIA) has worked with a range of leading Australian early childhood intervention practitioners and researchers to design an early childhood early intervention (ECEI) approach. This approach has been designed to identify the type and level of early intervention support needed to achieve the best outcome for the child.

The Ages and Stages Questionnaire (ASQ-TRAK) is a developmental screening tool that is used for monitoring and observing Aboriginal children's developmental progress until two years of age. NT Health is working with the NDIA to propose simplified reporting requirements to allow ASQ-TRAK results to be adequate documentation

required for NDIS Early Childhood Early Intervention Funding. If the child meets the NDIS's Early Intervention Criteria, a support package will be designed, and reviewed after 12 months, while the diagnosis process is further pursued.

NT Health is working closely with Aboriginal Community Controlled Health Services in Darwin and Alice Springs to assess children for neurodevelopmental disorders (including FASD) and connect them with appropriate early intervention and support services. The clinics have multidisciplinary teams which provide assessments of children through a single (virtual) setting, ensuring assessment can occur quickly and the child's support needs are recognised collectively.

This model of case management is preferable to establishing a designated FASD support service within NT Health as the Aboriginal Community Controlled Health Service is better placed to be able to maintain contact with the child and their family, regardless of the diagnosis, to ensure that effective care coordination occurs.

Confirmed consumption of alcohol during pregnancy assists with diagnosis of FASD. Midwives in Top End Health Service (TEHS) and Central Australia Health Service (CAHS) currently record alcohol use during pregnancy on maternal records during antenatal visits. Accurate documentation of antenatal alcohol use needs to be recorded and documented on any referral to child and family health services. NT Health will ensure this becomes routine practice for all health staff.

It is important to increase health literacy and build the capacity of families and communities to recognise and respond to neurodevelopmental impairment in children, especially in remote areas where access to specialist services are limited.

NT Health will implement a developmental assessment tool for use by families and other services to assist with identifying developmental delay and increasing awareness of signs of neurodevelopmental impairment in children. Families will also be empowered by gaining a better understanding of what to look out for in their children, giving them increased confidence to seek further assessment if concerned.

Primary Health Care Services play a key role in coordinating assessments and interventions for children with neurodevelopmental impairment. Within current resources, there will be a renewed focus on ensuring that primary health care staff are educated so that abnormalities can quickly be recognised and assessed. NT Health will increase the use of telehealth services for specialist advice when developmental concerns in children are identified, particularly in remote areas.

Although FASD is widespread and can affect anybody, there are populations where it is likely to be more prevalent. Targeted assessment of high risk populations such as those children born to mothers who are identified as alcohol dependant during pregnancy, children placed in out of home care or in the care of Territory Families, children who have siblings that have been diagnosed with FASD and youth in correctional facilities is needed.

Territory Families have a strategy in place to monitor FASD. There is an established procedure for when the health record of a child contains a history of prenatal alcohol exposure. If FASD is suspected a referral is made to a paediatrician for further assessment.

The transition between primary school to middle school is a key transition point for all students with an identified disability. Students transitioning to middle school may have a range of supports in place, such as a support plan, an Educational Adjustment Plan, a behavior plan, or receive specialist advisory support from NT Department of Education staff. The NT Department of Education's Psychology Team can provide middle schools with support and advice.

The NT Department of Education will disseminate information on FASD and the impacts it may have on classroom learning to all schools in an effort to increase awareness amongst teachers, reiterating the referral process to request support and guidance if required. FASD and its impacts, including effective strategies to support the student's learning, will be included in Professional Learning offered to teachers on an annual basis.

If FASD is not adequately recognised and managed in childhood, adults with unrecognised FASD may then go on to have their own children, some of whom may also be exposed to alcohol during pregnancy resulting in generational FASD. Assessment for neurodevelopmental disorders is focused on children throughout this strategy, however there are potentially many adults living

with unrecognised FASD who may also require support services and intervention to break the cycle. The importance of recognising and responding to FASD in adults should not be understated, and the broad awareness raising campaigns as well as targeted workforce education will help those in contact with adults who potentially have FASD to recognise and respond accordingly. Multi-disciplinary assessments will need to be conducted in order to obtain evidence of functional impairment.

For both children and adults with possible neurodevelopmental and functional impairments in need of support services, the first point of call is the NDIA. They can provide advice on NDIS eligibility and assessment requirements and further guidance on the processes to follow to gain access to the scheme.

Preliminary assessment and disability diagnosis as required for NDIS eligibility is the responsibility of the health system. Anyone approaching NDIA in the first instance without documented evidence of functional impairment will likely be referred back to the health system to obtain this information.

NDIS Local Area Coordination services may be available to help those who require additional assistance with linking to the NDIS and to mainstream and community supports.

The NT Remote Alcohol and Other Drug Workforce provide accessible and culturally safe services throughout the NT, including brief interventions with pregnant women. They are trained in culturally appropriate ways to have conversations with women

about alcohol use during pregnancy. Frontline workers receive training in brief interventions and motivational interviewing techniques. Further educating the workforce on FASD will be a key priority to improve the knowledge of workers who have contact with populations that are most at risk of having a child with FASD.

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### **The NT Remote Alcohol and Other Drug Workforce provide accessible and culturally safe services throughout the NT.**

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The Territory Government will ensure cultural safety, health literacy and linguistic background will be inherent in all assessments and interactions with individuals potentially impacted by FASD.

### **New Territory Government initiatives to recognise neurodevelopmental impairments (including FASD) in children**

The Territory Government will support the upskilling of staff currently situated in Aboriginal Community Controlled Health Services in targeted regions in the NT to take on the additional function of coordinating FASD interventions.

The Territory Government will support the establishment of neurodevelopmental assessment clinics within Aboriginal Community Controlled Health Services in targeted regions of the NT in collaboration with TEHS and CAHS so that comprehensive assessments can be conducted by multidisciplinary teams.

# 06

## Management and support for individuals and families impacted by FASD

FASD is a lifelong condition and there is no cure. However, it has been identified there are some parts of the brain that are able to be retrained and while it is unlikely the brain will achieve its full functional capacity, there are techniques that can improve brain function. Early interventions are associated with better long-term outcomes, so it is important that neurodevelopmental support needs are identified in children as early as possible. This will allow support services to be engaged, to lessen the impacts on the individual, families, teachers and carers.

The Territory Government recognises the importance of promoting the social and emotional wellbeing of individuals and families impacted by FASD. Integrating social and emotional wellbeing programs in schools is a measure that can be applied to create a safe and supportive learning environment for all children, including those with additional support needs.

Programs that help children to develop effective social and emotional skills and manage their own behaviour are beneficial for all children. These programs can also help to build protective factors such as resilience and community connectedness which can lessen the risks of mental health issues resulting in mental illness, antisocial and criminal behaviour, and alcohol and other drug issues or substance misuse disorders later in life.

### Adults with FASD

The type or level of support required for adults will differ compared to children and young people. Services for the duration of the individual's life must be considered taking into account the functional capacity of the individual.

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### FASD is a lifelong condition and there is no cure.

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The NDIS is available for people with functional disability related to FASD. The NDIS looks at the functional impairment of the individual and a diagnosis of FASD is not a requirement. The NDIA, as part of the access request process to the NDIS, will require evidence of the functional limitations of the individual. The NDIS package of support will be based on the evidence that is provided during this process.

In order to meet NDIS eligibility criteria a person must demonstrate they meet all of the following:

- a) The person has a disability
- b) The disability is likely to be lifelong (permanent)
- c) The disability results in significant functional impacts to everyday life in one or more of the following areas – communication, social interaction, learning, mobility, self-care or self-management
- d) The disability impacts social and economic participation
- e) The person is likely to require NDIS support for their lifetime.

NT Health will improve awareness of FASD among specific workforces such as public housing officers so that FASD will be considered and acknowledged in any interactions, and that support services are offered where appropriate.

### Families

Support programs such as the Australian Nurse-Family Partnership Program, Families as First Teachers, Healthy Under 5 Kids – Partnering Families program, Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council, Child Nutrition and Wellbeing Program and the Maternal Early Childhood Sustained Home-visiting program all aim to build the capacity of families to improve the developmental outcomes of children and provide support to their families. Programs such as the Parents Under Pressure program specifically aim to assist families that are raising children in difficult circumstances, using a strengths-based approach.

This program acknowledges the unique nature of every family and provides support within the home to develop parenting techniques using different exercises which help the parent work towards their parenting goals.

The Territory Government commits to further promoting the availability of resources and programs such as these. It also commits to improving the links to support services for families who birth a child with FASD, through supporting the assessment services to be established in Aboriginal Community Controlled Health Services in partnership with TEHS and CAHS.

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**Social and emotional wellbeing programs are also important for families impacted by FASD, to provide them with social and cultural support for their wellbeing and mental health as well as to encourage community connectedness.**

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### Schools

The Department of Education has a range of strategies to support staff who are teaching and working with students with FASD such as school psychologists work with paediatricians and allied health professionals to determine support needs.

The Department of Education has a suite of resources to support teachers with integrating students with FASD into the classroom and teachers have access to professional learning opportunities to develop teaching strategies and receive guidance about best practice to support students in a classroom setting.

Teachers, assisted by special education teachers, assistant principals, and/or principals develop Education Adjustment Plans for students who have been diagnosed with FASD, and these students may have an Individual Behaviour Plan, developed within their school with assistance from health professionals.

Schools play an important role in developing lifelong skills in children such as confidence, persistence, organisation, ability to get along with others and emotional resilience. These skills can assist children later in life to become strong and healthy leaders. Whole school programs that build these skills, as well as the use of trauma informed care principles, will be further promoted throughout all schools with a focus on all children, not just those impacted by neurodevelopmental disorders.

It is important to recognise the strengths of children who have neurodevelopmental disorders and focus on developing these strengths.

### Carers

Although it is unknown exactly how many children in out of home care services have FASD, a pilot study commissioned by Territory Families looked at a sample of children involved with child protection services in the Northern Territory during 2011-12. The study found that prenatal alcohol exposure was associated with children entering care, and that these children experienced more significant behavioural and health issues than others.

Territory Families currently provide training to staff to ensure they are equipped to recognise and manage support requirements of children affected by FASD. Territory Families has also developed the Tune into Little Ones Workers Resource Manual and Extra Concerns booklet which includes information about FASD and strategies to assist with caring for a child with FASD.

The Territory Government has announced an investment of \$2.77 million to support frontline workers in child protection, youth justice and domestic violence services. This funding will see the establishment of a Clinical and Professional Practice Directorate – a team of experts will work with frontline staff to improve their clinical practice and ensure staff have ongoing training, professional support, mentoring and coaching to assist them with the services provided.

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**The study found that prenatal alcohol exposure was associated with children entering care, and that these children experienced more significant behavioural and health issues than others.**

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While early intervention and assessment of children for potential FASD is important, connecting children that have neurodevelopmental disorders with support services is the next imperative step. Transitioning existing clients with disabilities to the NDIS is currently occurring and with increased support for neurodevelopmental clinics within Aboriginal Community Controlled Health Services partnered with TEHS and CAHS, a statement of functional impairment can be produced by these clinics which will assist with referral to the NDIS and mobilisation of support services for the child.



# 07

## Priority groups

In addition to focusing on the priority group of adolescents (both male and female) and women of childbearing age, there is a need to focus future activities towards youth in juvenile justice settings.

Telethon Kids Institute in Western Australia has recently undertaken a feasibility study of assessment, diagnosis and workforce development to improve the management of youth with FASD in the justice system. Titled 'The Banksia Hill Project', the study was conducted in Western Australia's only juvenile detention centre. Results released in 2018 suggest that as many as 36% of youth in detention have FASD<sup>11</sup>.

A recommendation from the 2016-17 Royal Commission into the Protection and Detention of Children in the NT is that on the admission of a child or young person to a detention centre, a comprehensive medical and health assessment is conducted including a behavioural assessment to determine whether the child should be referred for a formal FASD assessment.

Another recommendation being that if the need for a formal FASD assessment is identified, that this be funded through Medicare or the NDIS as appropriate.

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Results released in 2018 suggest that as many as 36% of youth in detention have FASD.

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NT Health will improve awareness of FASD within the Justice system. Lawyers and members of the judiciary will receive information sessions and materials to help them understand and consider the impacts that FASD can have on an individual's capacity to make sound decisions.

Another priority group is children in out of home care. Early assessment for neurodevelopmental impairment and linking these children with support services may prevent future contact with the juvenile justice system. The Territory Government will facilitate the assessment of all children in out of home care.

11 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

# 08

## Monitoring and evaluation framework

The consumption of alcohol during pregnancy has many impacts not only on the unborn child but also on the mother, the family and the community. A systematic approach is required to ensure that the response to addressing FASD considers any unintended consequences of initiatives introduced. It is therefore imperative that data is collected, monitored and evaluations of initiatives are conducted, to allow an evidence base to build on what is and isn't working to guide future investments.

Maternal alcohol consumption during pregnancy data is collected through the NT Midwives Data Collection which forms part of the National Perinatal Data Collection. Collecting self-reported information on alcohol consumption from the pregnant woman currently occurs at the initial visit and again at 36 weeks gestation, in all TEHS and CAHS antenatal clinics and in remote health clinics across the Northern Territory. This data relies on disclosure by the pregnant woman and stigma associated with disclosure may contribute to underreporting.

There is currently no ability to record clinician observation and patient history, which may also result in underreporting. Given the limitations of the current data, the Territory Government is committed to improving the collection of data to support the FASD diagnosis process.

A recommendation of the Alcohol Policies and Legislation Review which received in-principle support by the Territory Government was that

NT Health commission a prevalence study. Neurodevelopmental assessment clinics situated in Aboriginal Community Controlled Health Services in partnership with TEHS and CAHS will, with the consent of the individual, collect data during the assessment process to build on the knowledge of prevalence rates across the NT.

A data set will be developed by NT Health to allow monitoring and analysis of assessments undertaken and any resulting diagnosis, to establish the prevalence and incidence of FASD in the NT.

The Alcohol Harm Minimisation Working Group will facilitate cross-agency coordination of initiatives outlined within this strategy, and monitor activities delivered by agencies. This group of senior officers of all government departments is involved in all 33 projects being implemented to minimise alcohol related harm. NT Health will support smaller regional centres to establish FASD network groups for the purposes of sharing information between community members and frontline workers.

How we will measure our success:

1. Reduced rates of women consuming alcohol during pregnancy
2. Reduced wait times for assessments
3. Increase in neurodevelopmental assessments:
  - a) during early childhood
  - b) during middle school
  - c) of youth in the juvenile justice system
  - d) of children in out of home care.



