National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028

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Title: National Fetal Alcohol Spectrum Disorder Strategic Action Plan

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INTRODUCTION

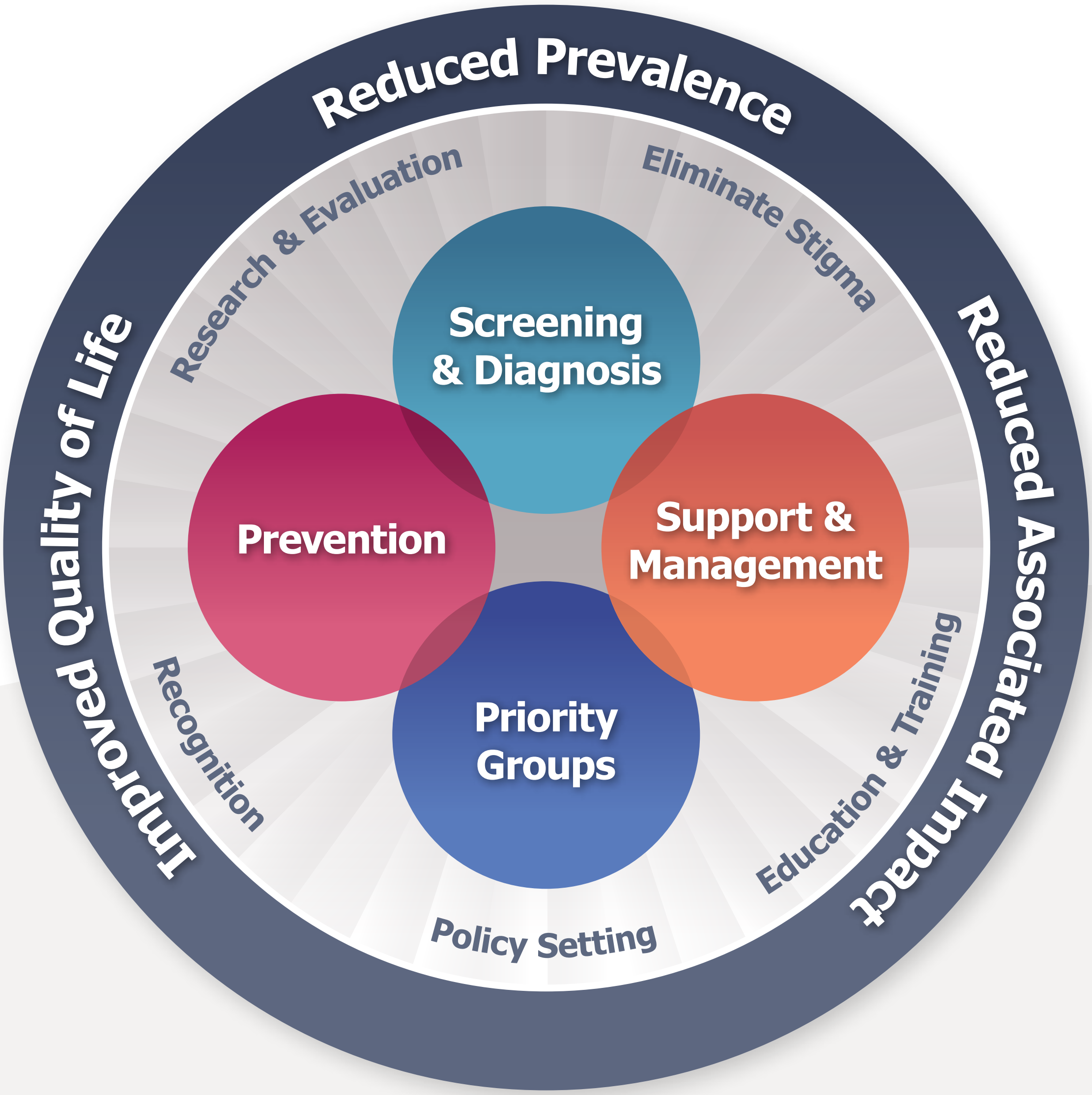
Introduction to the Plan

Purpose

The National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028 (the Plan) has been developed to provide a clear pathway of priorities and opportunities to improve the prevention, diagnosis, support and management of FASD in Australia. It builds on the significant foundational work and investment over recent years made by governments, non-government organisations, family advocates, researchers and clinicians, individual champions and communities who have raised awareness and supported individuals and their families living with FASD.

Aim

The Plan aims to reduce the prevalence of FASD and the impact it has on individuals, families, carers and communities. It identifies a series of priorities and opportunities to inform future approaches by governments, service providers and communities over the next decade.



The Plan recognises that with early and accurate diagnosis and early, individualised interventions for children and adults who have FASD along with appropriate support for parents and carers, the quality of life outcomes for individuals with FASD and their families can be substantially improved.

The implementation of the Plan should establish and strengthen partnerships with families and carers, and the organisations that support them, so that the extent and nature of the collateral impact of harms of FASD is considered and minimised.

Structure

The Plan is structured around four key national priorities to catalyse national efforts in the prevention, diagnosis, support and management of FASD in Australia over the next decade.

It adopts five **enablers** and seven **guiding principles** which should be embedded in the planning, design and implementation of all activities under the Plan.

The three key aims of the Plan are to:

- reduce prevalence of FASD;
- reduce the associated impact of FASD; and
- improve the quality of life for people living with FASD.

National priorities

- Prevention
- Screening and diagnosis
- Support and management
- Priority groups and populations at increased risk

Enablers

- Appropriate recognition of FASD as a disability
- Eliminate stigma
- Education and training
- Policy coordination
- Research and evaluation

Guiding principles

- **Collaboration and partnerships** – Use linkages and opportunities to cooperate and partner responsibly to achieve greater impacts than can occur in isolation.
- **Access** – Safe, high standard, appropriate prevention and support programs and services are available, accessible, equitable and affordable for all Australians.
- **Evidence-based** – Rigorous, relevant and current evidence informs best practice and strengthens the knowledge base to effectively prevent and manage FASD.
- **Population-wide, place-based and person-centred approaches** – Service providers shape services to recognise and value the needs of population groups, communities, individuals, carers and families, and to provide a continuum of care and support.
- **Sustainability** – Strategic planning enabling access to health and disability funding mechanisms (as appropriate), and responsible management of resources delivers long term improvements in the lives of those living with FASD.
- **Accountability and transparency** – Decisions and responsibilities are clear and accountable and achieve best value with public resources.
- **Shared responsibility** – All parties understand, accept and fulfill their roles and responsibilities in preventing and managing FASD in Australia.

Intended audience

The Plan is intended to inform decision and policy makers, and service providers at the national, state and territory and local levels. It is a resource for governments, the non-government sector, stakeholder organisations, local health service providers, private providers, industry and communities. It is also intended to act as a tool for those that advocate for people wanting to prevent the occurrence of FASD, those living with FASD and those impacted by FASD (including families and carers).

Development

In December 2016, the Australian Government Department of Health facilitated a roundtable with key FASD stakeholders and government agencies to discuss and review the **FASD Action Plan 2013-14 to 2016-17** (Action Plan)[1] and provide advice on the implementation of the 2016-17 Federal Budget Measure**-Taking More Action to Prevent FASD** (Budget Measure).[2] One of the key outcomes of the roundtable was the recommendation that a National FASD Strategy be developed for Australia to guide future efforts. This Plan responds to that recommendation.

Consultations

The Australian Government engaged Siggins Miller Consultants to assist with the development of the Plan. This process was informed by analysis of existing FASD policy and service frameworks, data and research evidence and extensive consultation with key stakeholders. Consultation involved a series of workshops held across the country in each state and territory, with a mix of capital city and regional locations. Those unable to attend the workshops were able to provide written submissions to help inform the development of the Plan.

Consultations involved:

- individuals and organisations working in the area of FASD, including those working directly with people affected by FASD and their families and carers;
- public health organisations;
- government agencies including health, community services, education, corrections and juvenile justice;
- the National Aboriginal Community Controlled Health Organisation (NACCHO) and affiliates; and
- representatives of the alcohol industry.

The consultations identified many gaps for people living with and/or impacted by FASD in accessing diagnostic, early intervention and support services. Issues around a lack of understanding of the behavioural manifestations of FASD in the home and in both educational and correctional settings were also raised.

Without improvements to address these issues, individuals with and/or impacted by FASD will miss out on supports to improve their quality of life.

Consultations also underlined the importance of recognising that FASD is a lifelong condition and that the specific disabilities and problems experienced by an individual will vary along a spectrum. Individuals require support and care that is tailored to and responsive to their needs across the lifespan.

This means that clinicians, service providers and organisations must have the capacity to develop strategies and deliver support on an individual basis according to the presenting behaviours and strengths.

A report detailing the consultation findings was provided to the National Drug

Strategy Committee (NDSC) to inform the finalisation of the Plan by the Australian Government and states and territories. A report detailing the consultation findings was provided to the National Drug Strategy Committee (NDSC) to inform the finalisation of the Plan by the Australian Government and states and territories.

Relationship with other national health strategies

The Plan is expected to align with, and inform the implementation of, a number of other key national health strategies and frameworks including the:

- *National Drug Strategy 2017-2026*;
- *National Alcohol Strategy 2018-2026* (under development at time of writing);
- *National Aboriginal and Torres Strait Islander People's Drug Strategy 2014- 2019*;
- *National Strategic Framework for Chronic Conditions (published in 2017)*; and
- *National Aboriginal and Torres Strait Islander Health Plan 2013-2023*.

The Plan recognises that there are a range of existing jurisdictional strategies and guidelines developed by professional associations and non-government organisations, as well as international frameworks, which consider the spectrum of interventions relevant to FASD.

It is envisaged the Plan will complement and build on these initiatives while identifying or confirming areas for further action over the next decade.

Importantly the activities identified under the priority areas are provided as examples that could contribute to making progress against the objectives of the Plan. The Plan recognises the importance of providing flexibility to tailor responses, policy interventions and funding to local priorities, needs and circumstances.

Fetal Alcohol Spectrum Disorder (FASD)

Definition

FASD is a diagnostic term for the range of physical, cognitive, behavioural and neurodevelopmental abnormalities which can result from maternal drinking during pregnancy. Australian and international guidelines advise that there is no safe level of prenatal alcohol exposure or exposure to alcohol while breastfeeding.[3] Alcohol crosses the placenta and may irreparably damage the brain and other organs of the developing embryo and fetus.[4]

The timing and intensity of alcohol exposure can contribute to the resulting fetal harm caused by prenatal exposure to alcohol. Alcohol may harm the fetal brain at any time during the pregnancy, although birth defects including facial anomalies result from first trimester exposure.

No safe level for alcohol consumption in pregnancy has been established. The dose, pattern and timing of prenatal alcohol exposure all influence the type of resulting adverse fetal outcomes.

Prenatal exposure at moderate (3-4 drinks per occasion) or higher levels increase the risk, type and severity of child behaviour problems, and the timing of exposure influences the type of behaviour problems exhibited. For example, for outcomes such as language delays, the risk to the fetus appears to be highest when moderate-to-heavy levels of alcohol were consumed in the third trimester.[5]

Not all exposure to alcohol in utero will have an effect, or the same degree or type of effect on the fetus. A number of complex and interrelated factors can influence the effects of alcohol on the fetus which include socio-economic factors, nutrition, substance abuse and trauma, combined with genetics.[6]

Research from the United States of America indicates that for one individual with FASD, the lifetime cost is at least $2 million ($USD).[7]

The diagnosis of FASD emphasises the primary importance of the severe neurodevelopmental impairment that results from an acquired brain injury caused by alcohol exposure before birth. Diagnosis is complex and ideally requires a multidisciplinary clinical team to evaluate individuals for:

- confirmation of alcohol exposure during pregnancy;
- neurodevelopmental problems (i.e. severe impairments due to abnormal development of the brain and central nervous system); and
- facial abnormalities in the context of a general physical and developmental assessment.

The *Australian Guide to the Diagnosis of FASD* recommends that the diagnosis be divided into one of two sub-categories:

1. FASD with three sentinel facial features (similar to the previous categories of Fetal Alcohol Syndrome without a requirement for growth impairment), or
2. FASD with less than three sentinel facial features (which encompasses the previous partial Fetal Alcohol Syndrome and neurodevelopmental disorder – alcohol exposed category).[8]

Further information on the Australian diagnostic criteria can be found at www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/guide-to-diagnosis.

FASD has lifelong consequences and can lead to significant secondary impairments, such as difficulties accessing education services, substance use, mental ill-health, difficulties living independently, problems obtaining and maintaining employment and early contact with the justice system.[9] Individuals with FASD have a shortened lifespan with an average life expectancy of only 34 years of age.[10]

FASD results in a broad range of costs to those with the condition, their families and carers, and to the community. These costs include health care and accommodation, education, employment support services, income support, community and justice services.

Prevalence

FASD affects many communities – it is not isolated to a specific country, region or population group. While, Australia does not have national FASD prevalence data, and there is general agreement among researchers and practitioners that rates are underestimated.

The global prevalence of FASD among children and youth in the general population was estimated to be 7.7 per 1000 population.[11] Research indicates that prevalence estimates are higher that assumed thus far, and clear guidelines on assessing FASD prevalence are required.[12] A recent study of alcohol use during pregnancy and FASD prevalence estimated that one in every 67 women who consumed alcohol during pregnancy would deliver a child with FASD, translating to around 119,000 children born with FASD in the world every year.[13]

Estimates based on state and territory data indicate likely rates at 0.01 to 0.68 per 1,000 births in the total population. However, there are concerns that these figures are likely to underestimate the rates of FASD[14] and that as many as 2% of all Australian babies may be born with some form of FASD.[15]

Prevalence of FASD in vulnerable populations is higher. Among Aboriginal and Torres Strait Islander Australians estimates indicate that the incidence of FASD may range from 1.87 to 4.7 per 1,000 births.[16]

A study conducted in the remote Fitzroy Valley Indigenous community in Western Australia found very high rates of FASD in many remote communities, with the number of cases diagnosed at 194 per 1,000 births for children born between 2002 and 2003.[17]

A recent study on the prevalence of FASD within the juvenile justice system found that 36% of 10-18 year olds in Banksia Hill Detention Centre (WA) were diagnosed with FASD.[18]

The prevalence of FASD in Australia is difficult to determine due to several factors, including a lack of routine assessment and screening for maternal alcohol use and FASD, a lack of national diagnostic criteria until recent times, a lack of nationally consistent data collection and reporting, and a lack of awareness of the full spectrum of disorders in FASD.

Achievements over the last decade

This Plan recognises that all sectors across the Australian community – all levels of government, non-government organisations, communities and individuals – play an essential role in the prevention of FASD and in supporting individuals living with and/or impacted by FASD, including families and carers.

Foundational efforts by all stakeholders over many years have played a major role in raising awareness of FASD in the community, among health professionals and having the issue prioritised by governments. The result of these efforts is a substantial body of policies, programs, resources and tools. Examples of these are summarised below.

National actions

FASD in Australia: An Update, 2009 (the Monograph) [19]

The Monograph, commissioned by the former Intergovernmental Committee on Drugs, was developed by a Working Party on Fetal Alcohol Spectrum Disorder. This was a seminal work which has informed and guided FASD policy development and action in Australia. It examined FASD developments in Australia and overseas and identified best practice approaches to reduce the incidence of FASD, particularly in Indigenous communities. The findings identified areas for additional attention and enhancements to existing practices to improve prevention, early intervention and long-term management of FASD.

FASD: The Hidden Harm – Inquiry into the Prevention, Diagnosis and Management of FASD (the Inquiry) [20]

The Inquiry by the Standing Committee on Social Policy and Legal Affairs, House of Representatives, was tabled in November 2012. It reported on the development of a national approach to the prevention, intervention and management of FASD in Australia, with particular reference to:

- prevention strategies, including education campaigns and options, such as product warnings and other mechanisms to raise awareness of the risks associated with prenatal alcohol consumption;
- intervention needs — including FASD diagnostic tools for health and other professionals, and the early intervention therapies aimed at minimising the impact of FASD on affected individuals;
- management issues, including access to appropriate community care; and
- support services.

On 25 June 2014, the Australian Government announced the FASD Action Plan (Action Plan) which committed funding of $9.2 million over four financial years (2013-14 to 2016-17).

The **Action Plan** ensured that Australian Government funds were directed to the provision of better diagnosis through the development of the Australian Guide to the Diagnosis of FASD and training, information services (including establishment of www.fasdhub.org.au), advisory networks, improving data collections (including establishment of the National FASD Register), family support, development of best practice interventions and services to support high-risk women and awareness/ prevention activities.

In the 2016-17 Budget, the Australian Government provided a further $10.5 million over four years from 2016-17 to 2019-20 to build on the achievements of the Action Plan. The Budget Measure provides funding for activities such as online and telephone support for individuals and families affected by FASD, further prevention activities and the provision of on-the-ground FASD diagnostic services and models of care in communities of high need.

Research

Research on FASD is continuing to grow and provide the evidence-base for governments to implement policies and programs to prevent, support and manage FASD in Australia. The Australian Government, through the National Health and Medical Research Council (NHMRC), funded the Reducing the Effects of Antenatal Alcohol on Child Health (REAACH) Centre of Research Excellence (CRE), now known as the FASD Research Australia CRE, funded between 2016 and 2020.

The CRE will contribute to the sustainable empowerment of communities, organisations and professionals to address FASD, and to reduce its compounding impact on affected children, their families and the wider community.

Currently there are two research hubs based in Perth and Sydney and a database of all past and present research on FASD, which is maintained by the CRE and available on the FASD Hub Australia (www.fasdhub.org.au).

State and territory policies and programs

States and territories deliver a range of services in relation to prenatal alcohol exposure and/or FASD. Detailing these services for each jurisdiction is beyond the scope of the Plan. In broad terms, states and territories provide the following types of services:

- Assessment of alcohol consumption in pregnancy, a process undertaken by child and maternal health/antenatal/obstetric services, which provide referral to appropriate services where required.
- Identification of substance use in pregnancy with brief intervention support for substance use and follow up of mother and child after birth.
- Provision of Aboriginal maternal and infant health services by Aboriginal Community Controlled Health Services and local health districts.
- Delivery of specialist drug and alcohol treatment by appropriate assessment and treatment services.
- Provision of information, coaching and resources about healthy pregnancy and alcohol use as well as support and treatment options for the community.
- Delivery of Aboriginal and Torres Strait Islander-specific alcohol and pregnancy initiatives focused on information and raising awareness.
- Provision of training and education for health and community service workers.
- Reduction of risky alcohol use and related harm by limiting alcohol availability and implementing pricing and promotion controls.

In numerous regions there are large-scale FASD prevention activities underway. These include in the Kimberly and Pilbara regions of WA, Central Australia and the Hunter-New England region of NSW. These FASD prevention activities are linked to an international FASD prevention collaboration with Canada, South Africa and the Netherlands.

Looking forward – the next 10 years

As mentioned earlier in the Plan, following the December 2016 roundtable meeting which reviewed the Action Plan, the need for a new national strategic framework to guide activities and actions was identified.

It was during this discussion that the priority areas emerged which were further informed through national stakeholder consultation. The Ministerial Drug and Alcohol Forum (MDAF) thanks those who participated in the development of the Plan.

The activities and actions outlined in the priority areas of the Plan are intended to guide future action. They are not compulsory and can be adopted as needed, along with other interventions and programs, based on local needs. Activities should be evidence informed and based on best available research and data.

Actions should be tailored to individual communities and regions to cater for local contexts and environments. In tailoring interventions to local needs, it is important that activities remain aligned with the priority areas and objectives outlined in the Plan.

Further, while overarching alcohol controls and policy issues such as promotion, price, availability and accessibility can have a role in reducing the prevalence and impact of FASD, they are best placed for consideration through the National Alcohol Strategy (NAS) (currently under development) in the context of reducing a broader range of alcohol related harms. The Plan identifies opportunities with specific reference to FASD and expects that the implementation of the Plan will be a key focus of the NAS.

Finally, it is important to acknowledge that responsibility for some of the priorities and actions identified in this Plan sit outside the portfolios represented on the NDSC or MDAF. It is also important to acknowledge that other social determinants of health and wellbeing can impact prevalence, availability of support and exacerbate effects of FASD on individuals, families and communities. As such, it will be critical for strong links to be established within and across governments, portfolios, service sectors and jurisdictions to ensure progress against the aims of the Plan.

NATIONAL PRIORITY AREAS

Prevention

Current Australian guidelines recommend that women abstain from alcohol when planning a pregnancy, during their pregnancy, and when breastfeeding, because no safe level of alcohol consumption has been established.[21]

However alcohol use is common among pregnant women in Australia. Around 47% of women consumed alcohol before knowing they were pregnant. The 2016 National Drug Strategy Household Survey reported that approximately 1 in 4 women continue to drink alcohol once becoming aware they were pregnant. A 2015 study reports that the number of women who drink once becoming aware they are pregnant falls to around 18%, however over 10% continue to drink making no reduction.[22]

Other research reports that the percentage of women drinking during pregnancy falls to about 7% after the first trimester.[23] However another study reported almost a third of Australian of women, approximately 27%, continue to drink while pregnant.[24]

Some women may not be aware of the potential harm of drinking during pregnancy. One study found that 39% of women surveyed were unaware that alcohol consumption during pregnancy could harm their fetus.[25] While approximately 55% had heard of FASD, 16% were unaware that alcohol use during pregnancy could cause lifelong disabilities.[26]

About 20% of women had a ‘neutral, tolerant or positive’ attitude to alcohol use in pregnancy and of those women who have previously given birth, 34% reported drinking in their most recent pregnancy. When asked what they would do in future pregnancies, 31.6% said they would continue to drink alcohol.[27]

The factors that are associated with alcohol consumption in pregnancy are complex. Women may have limited information about the risks of drinking during pregnancy, may be alcohol dependent, subject to domestic violence, living in poverty, malnourished, part of a community with social norms which promote drinking or experiencing mental ill health.[28]

Research has shown drinking during pregnancy appears to be consistently associated with women’s pre-pregnancy alcohol consumption (i.e. quantity and frequency of typical drinking) as well as exposure to abuse or violence.[29] Prevention strategies must be formulated to respond to potential influences on women’s alcohol consumption during pregnancy and identify women who may be at a higher risk and require targeted interventions.[30]

Australian research found that 75% of women who drank during pregnancy usually drank with their partner, and that many stated that drinking was often initiated by a partner.

Social and cultural determinants of why women drink in pregnancy include factors that are influenced by partners, such as exposure to intimate partner violence, high life stress, and substance use in the home.[31]

This underlines the need to ensure that responsibility for prevention of FASD is not placed on women alone and interventions focus on partners and families as well as changing the wider social norms that promote drinking.

The Plan recognises the crucial role played by all health professionals in FASD prevention – more than 50% of women identify health professionals as their preferred information source about alcohol use in pregnancy.[32]

Pre-pregnancy counselling provides an opportunity to discuss alcohol consumption with women and their partners. It also provides opportunity to identify and assist women who are at risk to access the treatment and increased support needed to reduce the risk of alcohol-related harm to the fetus.[33]

Stigma and fear of negative consequences may cause women to under-report alcohol consumption during pregnancy.

Failure to ask and advise about alcohol use represents a missed opportunity for both treating women and preventing FASD.

In one study, only 45% of doctors routinely asked about alcohol consumption in pregnancy and only 25% routinely provided information about the consequences of alcohol use during pregnancy. The same study reported that only 13% of doctors provided advice consistent with the current Australian Guidelines.[34]

Where screening is not universal, women who are disadvantaged or marginalised tend to be targeted and disproportionately reported to child protection services, whereas substance use by women of higher socioeconomic status does not elicit the same response.[35]

Implementing universal screening with all pregnant women as routine practice is vital to prevention and supports general practitioners (GPs), nurses and midwives to overcome discomfort with asking women about their alcohol use during pregnancy.[36]

Health practitioners have an important role to play in prevention of FASD as they are in a position to give timely, compassionate and competent prenatal care. This should include clear messages about the risks and consequences of alcohol consumption in pregnancy, brief interventions for those using alcohol during pregnancy, and specialised treatment for women who are alcohol dependent.

As almost half of all pregnancies in Australia are unplanned, it is imperative that health professionals ask patients about alcohol consumption prior to pregnancy awareness when unintended fetal exposure to alcohol is common.[37]

Integrating evidence-based FASD information into education and training programs for health practitioners would help raise awareness and prevent FASD.

Australian, state and territory governments have a long-standing commitment to evidence-based interventions known to decrease access to and modify alcohol use. The Plan seeks to build on the success of these interventions which can make a fundamental contribution to FASD prevention.

The **National Drug Strategy 2017-2026** and relevant sub-strategies, including the **National Aboriginal Torres Strait Islander People's Drug Strategy 2014-2019** and the **National Alcohol Strategy 2018-2026** (which is under development at the time of writing), provide comprehensive national frameworks focused on preventing and minimising alcohol and other drug-related, health, social and economic harms among individuals, families and communities.

Continued monitoring and evaluation of actions implemented under these national frameworks will ensure that the various levels of government are assessing progress being made, continually examining gaps and emerging issues and promoting interventions that can demonstrate positive impacts on outcomes.

This Plan aligns with the National Drug Strategy 2017-2026 and relevant sub-strategies to outline opportunities for consideration by decision and policy makers, and service providers at all levels to prevent, manage and support FASD in Australia. It acknowledges that there are a range of existing initiatives and resources throughout Australia which focus on supporting prevention efforts, especially in vulnerable groups, which could be extended, expanded or refined to maximise outcomes.

In addition, this Plan recognises the need to ensure that FASD interventions are culturally appropriate and developed in conjunction with Indigenous communities.

PRIORITY OBJECTIVES

Objective: Reduce access and consumption of alcohol in the Australian community

Activities that could contribute to the objective

- Highlight the issue of FASD in consideration of overarching policy responses and action taken through the National Alcohol Strategy 2018-2026.
- Continue to monitor evidence-based measures and assess suitability for implementation to reduce access to and risky consumption of alcohol.
- Continue to support at-risk groups and communities to implement local restrictions in their communities, such as decreasing opening hours, limiting take-away alcohol to low strength beer only, and legislating dry communities.

Objective: Increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy

Activities that could contribute to the objective

- Develop, implement and evaluate public education campaigns about the harms and consequences of alcohol consumption during pregnancy that: engage both women and their partners, are culturally appropriate, are informed by community knowledge, attitudes, values and drinking practices, and are fully consistent with national guidelines.
- Improve alcohol consumption information collected in the woman held maternal health record, antenatal clinical records, hospital in-patient records, GP and obstetrics and gynaecology records and encourage health professionals to discuss alcohol consumption throughout the planning/pregnancy/breastfeeding periods.
- Develop, implement and evaluate targeted education for high risks groups, such as women with alcohol dependency, women with FASD and other impairments to decision-making, young women in the criminal justice system and Indigenous communities where there are high levels of alcohol consumption and related harm.

- Extend models of care to incorporate a continuum inclusive of preventing FASD with a preventive approach addressing the behavioural, structural and environmental contributors to risky alcohol use.
- Provide access to supportive services for pregnant women (and those planning pregnancy) and their partners. This could include evidence-based information regarding alcohol use in pregnancy, brief interventions, advice on explaining contraception options, and providing specialised treatment for pregnant women who are alcohol dependent.
- Ensure adequate women/family centred support for alcohol dependent women of child bearing age that are specialised, culturally specific and accessible.

Screening and diagnosis

There are a number of points where universal and targeted screening can occur to assess the possibility that an individual has FASD, such as with newborns and during early childhood or enrolment at school. Routine screening of alcohol use for all pregnant women is discussed under **Prevention**.

This section focuses on the use of screening to assess the possibility that an individual has FASD, while diagnosis defines the nature of the disorder and helps to inform support and management strategies.

Developmental screening in infancy and preschool by health professionals can identify concerns and provide the basis for referral for more detailed screening and, if indicated, diagnosis of FASD. While screening may identify a child at risk of FASD, it will not always be possible to make a diagnosis at that point in time, and many children at risk of FASD need paediatric follow-up and assessment where appropriate.

Targeted screening can be implemented for groups at higher risk of FASD, including:

- children of mothers who are alcohol or drug dependent;
- babies that are small for gestational age and/or microcephalic;
- children in the care of child protection services and those who have been placed in adoptive care;
- children in child development or mental health services, especially those referred for problems with attention, behaviour or social/emotional development;
- children with a diagnosis of intellectual disability who do not have an established genetic aetiology; and
- siblings of children identified as having FASD.

Other groups at risk include:

- children referred to school psychology services for behavioural and learning difficulties;
- those referred to child and adolescent mental health services; especially where Attention Deficit and Hyperactivity Disorder (ADHD) is identified;
- youth in correctional settings; and
- children from regions or communities with high levels of alcohol use.[38]

The accurate diagnosis of FASD requires assessment by a range of clinicians. The gold standard is that the assessment and diagnosis will be conducted by a specialist multi-disciplinary team, including a paediatrician or adolescent physician and psychologist with any combination of a speech pathologist, occupational therapist, social worker and physiotherapist.[39]

However, where access to specialist teams is limited, it is important that other health and community service professionals are equipped to detect the possibility of FASD and contribute to the diagnostic process.

All health professionals, including child health nurses and GPs, as well as teachers and parents who have concerns about neurodevelopmental delay on screening, should be able to seek a referral from a GP to a developmental or general paediatrician, or to a specialised FASD assessment clinic if alcohol is considered as a possible cause for the delays experienced.

The *Australian Guide to the Diagnosis of FASD* (the Guide) was developed to educate clinicians, to standardise and streamline FASD diagnoses, and to ensure that the Australian diagnostic framework is consistent with comparable countries.[40]

The Guide can be used in many different ways by health professionals at every level. For example, a GP recognising likely alcohol exposure in utero could refer a child to a paediatrician for full diagnosis, and a paediatrician with concerns about speech and language problems could refer a child to a speech therapist.

Access to screening and diagnostic services in rural and remote locations is often limited. This is a crucial issue as these geographic locations are frequently high-risk areas, and where it can be difficult to engage women in relation to health, particularly those in Indigenous communities.[41]

Given workforce and service limitations, primary health care providers in remote locations can play a key role in the coordination of screening services.

A key objective under the Plan is to consider how access to appropriate and evidence-based diagnosis and support services can be improved. Existing programs and screening tools (including those being used internationally) should be examined and combined with strategies to ensure appropriate communication and training is delivered to professionals engaged in these programs. Access to support services is discussed further in **Support and Management**.

PRIORITY OBJECTIVES

Objective: Increase screening, diagnostic skills and knowledge in frontline professionals

Activities that could contribute to the objective

- Examine opportunities to improve access to appropriate and evidence-based diagnosis and support services through existing programs (such as the Medicare Benefits Schedule), and to ensure appropriate communication and training to professionals engaged in these programs.
- Work with primary health networks and other health service providers to enable practitioners to encourage discussion of alcohol consumption with all women of childbearing age, and build the capacity of practitioners to appropriately respond to women who identify alcohol use during pregnancy.
- Review the Australian Guide to the Diagnosis of FASD and ensure alignment with international best practice diagnostic tools and adoption of emerging evidence-based practices and appropriate referral pathways.
- Build on efforts to disseminate and train medical and health professionals in the *Australian Guide to the Diagnosis of FASD* and the *Australian FASD Diagnostic Tool and Referral Guidelines*.
- Support the dissemination and use of tools and training for assessing child development in a range of health care settings to assist in identifying all forms of neurodevelopmental impairment, and as an alert for potential further assessment to determine if FASD is present. Training must stress that one cause of neurodevelopmental impairment which needs to be considered is alcohol exposure during pregnancy.

Objective: Improve capacity for screening, diagnosis and surveillance

Activities that could contribute to the objective

- Develop and trial a FASD pre-screening tool for use in a wider range of health services, including child and maternal health services and adolescent health services.
- Develop a FASD screening tool and response system for high risk groups such as youth entering correctional settings.
- Draw on lessons from the suite of FASD diagnostic services and models of care implemented across Australia and disseminate best practice models to assist existing interdisciplinary teams, such as child health nurses and child and family services, to contribute to the FASD diagnostic process in the context of their service model.
- Continue to improve national prevalence data on FASD for Australia.

Support and management

Many people with FASD are not identified until relatively late in life, or not at all.[42] In particular, adolescents with FASD are often undiagnosed, and may be accessing multiple support services including for alcohol and other substance use, mental health and criminal justice. Evidence shows that early identification and tailored intervention improves life outcomes for individuals affected by FASD.[43]

Research indicates that there are a range of social, behavioural and pharmacological interventions which have been shown to benefit the lives of individuals with FASD and their families through helping to manage the secondary conditions those with FASD experience.[44]

The range of impairments associated with FASD can lead to significant secondary disabilities, including substance abuse and mental health problems, as well as reduced ability to live independently, difficulty obtaining a job and increased contact with the criminal justice system.

This emphaises the importance of programs which prevent and limit the extent of secondary conditions being available to individuals across the lifespan, which are individualised, comprehensive and coordinated across developmental stages.[45]

There is broad agreement that multidisciplinary models of care are optimal for the management, support and care of individuals with FASD. The nature and type of disability experienced by the individual varies, requiring a personalised program of care.

People with FASD experience many co-morbid conditions. Increased rates of mental health and alcohol and drug problems are common and ADHD and intellectual disability rates are much higher in the FASD population.

Routine consideration of FASD in the diagnosis and management of mental illness and developmental disorders is important as psychosocial risk factors can compound the effect of FASD, including exposure to other substances prenatally, childhood trauma or neglect, and multiple care placements. Service development and care planning should consider the range of adversities children and their families may have experienced.

Increasing access to appropriate, evidence-based diagnosis and support services is a crucial strategy for improving care and support for people with FASD and their families. This Plan seeks to explore existing funding mechanisms to see how such improvements can be achieved – see also **Screening and Diagnosis**.

Models of care are likely to differ in urban, rural and remote settings in response to different cultural needs. Importantly, models should reflect a multidisciplinary approach that reflects the needs of the individual, bringing clinical and non-clinical providers together (such as health, education, child protection, employment, housing and justice) to determine the most appropriate models and service pathways.

Such teams can also liaise with education, child protection, justice and other services to determine the most appropriate model of care for an individual with neurodevelopmental delays, including those affected by FASD.

The **Pregnancy Care Guidelines**, released in February 2018, are designed to support Australian maternity services to provide high-quality, evidence-based antenatal care to healthy pregnant women. They are intended for all health professionals who contribute to antenatal care, including midwives, obstetricians, GPs, practice nurses, maternal and child health nurses, Aboriginal and Torres Strait Islander health workers and allied health professionals.

They cover the importance of addressing alcohol consumption during pregnancy and the support and treatment required for alcohol use, or where a baby is suspected to have FASD.

The Pregnancy Care Guidelines are designed for national, state, territory and local implementation to provide consistency of antenatal care in Australia and to ensure maternity services provide high-quality, evidence-based maternity care.

The section of the Pregnancy Care Guidelines covering alcohol consumption during pregnancy and FASD issues are expected to be revised as the review of the overarching NHMRC **Australian Guidelines to Reduce Health Risks from Drinking Alcohol** is undertaken (underway at time of writing).

A diagnosis of FASD can place a substantial burden on parents, carers and families. Evidence supports the benefits of parent/carer-centered training programs, which increase the understanding of behavior in terms of the underlying brain dysfunction, target interventions that promote child, individual and family function, and provide support to manage problem behaviors.[46]

Australia has implemented several initiatives which are making a significant contribution to addressing this Priority, including the provision of FASD Diagnostic Services and Models of Care in communities of high need across both metropolitan and non-metropolitan areas. The Australian FASD Diagnostic Tool and Referral Guidelines is providing increased access to diagnostic services and providing education and resources to communities at high risk of FASD. The services also provide appropriate referral services to those diagnosed with FASD and their families.

The FASD Hub (www.fasdhub.org.au) provides a central repository for all information on FASD for clinicians, health practitioners, researchers and consumers. In addition, the National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) Australia provides information services to individuals and families affected by FASD.

An online and telephone support service for individuals affected by FASD, their parents, carers, service providers, clinicians and community workers is also available through NOFASD Australia at www.nofasd.org.au or 1800 860 613.

Individuals with FASD often experience difficulties at school and are likely to have complex needs which are difficult to meet within a regular classroom. Implementing specialised programs that recognise and address the particular needs of children with FASD in schools would contribute toward improving life outcomes.

This may involve tailored training for teachers focussing on: evidence-based FASD education practices, knowledge of learning and behavioural characteristics of children living with FASD, evidence-based strategies to meet the needs of children and young people in schools and classrooms, and comprehensive assessment and individualised education plans (IEP) developed by a multidisciplinary team.[47] Practical guidance for teachers is provided in the resource 'Understanding and addressing the needs of children and young people living with FASD – A resource for teachers'.

Children with FASD in some communities may live in non-traditional family structures, move between families over time or be in and out of foster or supported care. Increasing flexibility and payments linked to the individual child could assist in overcoming barriers in providing support.

PRIORITY OBJECTIVES

Objective: Implement and evaluate better models of management, support and care

Activities that could contribute to the objective

- Implement and evaluate multidisciplinary models of care which recognise that children diagnosed with FASD may have a range of comorbidities and social disadvantage, resulting in complex developmental and behavioural issues which require services across the lifespan. The models of care should reflect the principles that interventions must be evidence-based, individualised, accessible, coordinated, culturally appropriate and developed in consultation with families and communities.
- Examine applicability of existing programs (including the National Disability Insurance Scheme) for providing families and individuals with greater access to support services.
- Disseminate best practice resources for the treatment of women with substance use disorders in line with current practice of specialist treatment service providers and developed under the Action Plan.
- Evaluate the various models of care to consider scalability and in particular how findings and service models could be applied in other locations where FASD prevalence is high and health and community services are limited.
- Encourage mental health and alcohol and other drug services to routinely consider FASD in the diagnosis and management of mental illness, substance misuse and developmental disorders, and support management interventions which recognise and respond to higher rates of self-harm and suicide, social isolation and poor self-esteem in individuals with FASD.
- Review legislation and policies at Commonwealth, state and territory and local government levels to ensure FASD is appropriately recognised as a disability, and make changes as required.

Objective: Support for parents, carers and families and in education and employment settings

Activities that could contribute to the objective

- Continue to expand the range and type of FASD resources available to individuals, their families and carers, including information about the diversity of support services available (e.g. suicide prevention programs, sporting programs, peer and family support groups, parent training programs, vocational and training services), and provide FASD training to frontline workers engaged in these support programs.
- Work with the education sector to implement specialised programs in schools that address the particular needs of children with FASD, including education and training for teachers about FASD, evidence-based classroom strategies, and involvement in delivery of individualised education plans (IEP).
- Promote the availability of evidence-based resources for parents, carers, and families in education and employment settings.

Priority groups

Any woman or group in society who consumes alcohol at harmful levels during pregnancy is potentially at risk of giving birth to a child with FASD. Some groups within Australian society are at higher risk than the general population because of their patterns of alcohol consumption.

Women who are alcohol dependent are at higher risk of having a child with FASD. Women who have given birth to children with FASD and continue to drink are at very high risk of having an additional child with FASD.

Studies consistently report that women who have had one child with FASD, and who continue to drink, have progressively more severely affected children with subsequent pregnancies.[48]

Australian studies have found high rates of FASD in some Indigenous communities. In general, fewer Indigenous women drink than non-Indigenous women - 71% compared with 77%. Indigenous women of child bearing age (18-44 years) are less likely to drink at low risk levels than non-Indigenous women of child bearing age (28.4% compared with 42%).

However, they are more likely to drink at risky/high risk levels (11.6% compared with 9.5%). Analysis shows that 80% of mothers of Indigenous children aged 0-3 years did not drink during pregnancy, 16% drank less, and 3.3% drank more or the same amount of alcohol during their pregnancy than when they were not pregnant.[49]

The impacts of social and economic determinants of alcohol use need to be carefully considered in any intervention. Indigenous women have reported that they drink to deal with stress and disadvantage, including the impact of historical trauma, loss of language, land and culture, domestic violence and geographic isolation.[50]

Across Australia, a range of programs have been implemented in Indigenous communities where there is increased FASD risk. These include the: Lililwan Project, Western Australia; the FASD prevention program in the Kimberley region; Strong Spirit Strong Future; StayStrong and Healthy: pregnancy resources for Aboriginal women, NSW; resources developed as part of the Anyinginyi Fetal Alcohol Spectrum Disorder Project in Tennant Creek, Northern Territory; and the Jandu Yani U (positive parenting) program in Fitzroy Crossing Western Australia. These programs underline the need for policy makers to work with Aboriginal elders, communities and organisations to develop Indigenous specific projects, with initiatives that are responsive to the broader social context in which they are implemented.

The Australian Indigenous Alcohol and Other Drugs Knowledge Centre (Knowledge Centre) provide online resources for workers and communities in regional, rural and remote areas involved in efforts to reduce harmful use of alcohol and other drugs in Aboriginal and Torres Strait Islander communities. The Knowledge Centre allows people to find culturally appropriate services by state, territory and region through an interactive map of Australia (aodknowledgecentre.ecu.edu.au).

Evidence suggests that binge drinking may be especially harmful to the fetus, and Australian data indicates that young people are more likely to binge drink.[51] This, in combination with the fact that around half of all pregnancies are unplanned, underlines the need for targeted strategies for young women.

The national alcohol strategies (past and present) have supported action to reduce the alcohol related harms experienced by at-risk populations, including teenagers and young people as well as a number of other vulnerable populations. Young women living with FASD are also at higher risk of having a child with FASD.

The intellectual, behavioural and social challenges associated with FASD may result in an increased risk of contact with the criminal justice system. When people with FASD do come in contact with the criminal justice system, these challenges mean they will have an impaired ability to navigate the system effectively, including diminished competence or capacity to stand trial.[52] The over-representation of people with FASD in the criminal justice system and the difficulties they face in dealing with the system underlines the necessity of a range of changes to better respond to the needs of those with FASD.

International research indicated that 11-23% of youth in juvenile detention had a diagnosis of FASD, youth with FASD were at 19 times greater risk of incarceration, and 60% of youth with FASD had previously had contact with the law.[53]

While there are very limited data in Australia, a study in Western Australia found that in Banksia Hill youth detention facility, 89% of inmates had at least one form of severe brain impairment (severe neurodevelopmental impairment) and 36% had a diagnosis of FASD.[54]

These findings point to the need for the criminal justice system to identify early and better respond to the needs of those with FASD. Therapeutic jurisprudence provides a conceptual analysis of the way in which the processes used by courts, judicial officers, lawyers and other justice system officers can impede, promote or be neutral in relation to outcomes connected with the participant's wellbeing.

Developed by Professors David Wexler and Bruce Winick in the United States of America in the 1980s in the context of mental health law, therapeutic jurisprudence is now seen to apply to all areas of the law and across cultures and is the subject of international study and development.

The criminal justice system has implemented therapeutic jurisprudence in its response to the specific needs of some Australian populations, such as drug offenders, through models of drug court and diversion programs, and offenders with mental health disorders and intellectual disabilities. The approach should be applied as broadly as possible in regard to individuals with FASD.

Equipping the juvenile justice system, including probation workers, police officers, detention workers, staff in correction facilities, through-care case workers, shelter homes, and mental health facilities with the knowledge, skills and resources to provide appropriate services, would improve the outcomes for young people with FASD.

Where an offender is affected by FASD and must receive a custodial sentence, therapeutic secure care facilities as an alternative to prison should be considered.

In Indigenous communities, support for the implementation of diversionary programs which involve community-controlled processes ‘on-country’ to provide a culturally secure and appropriate environment for children with FASD is important.[55]

PRIORITY OBJECTIVES

Objective: Continue to support and evaluate targeted strategies and models of care for groups who are at higher risk than the general population

Activities that could contribute to the objective

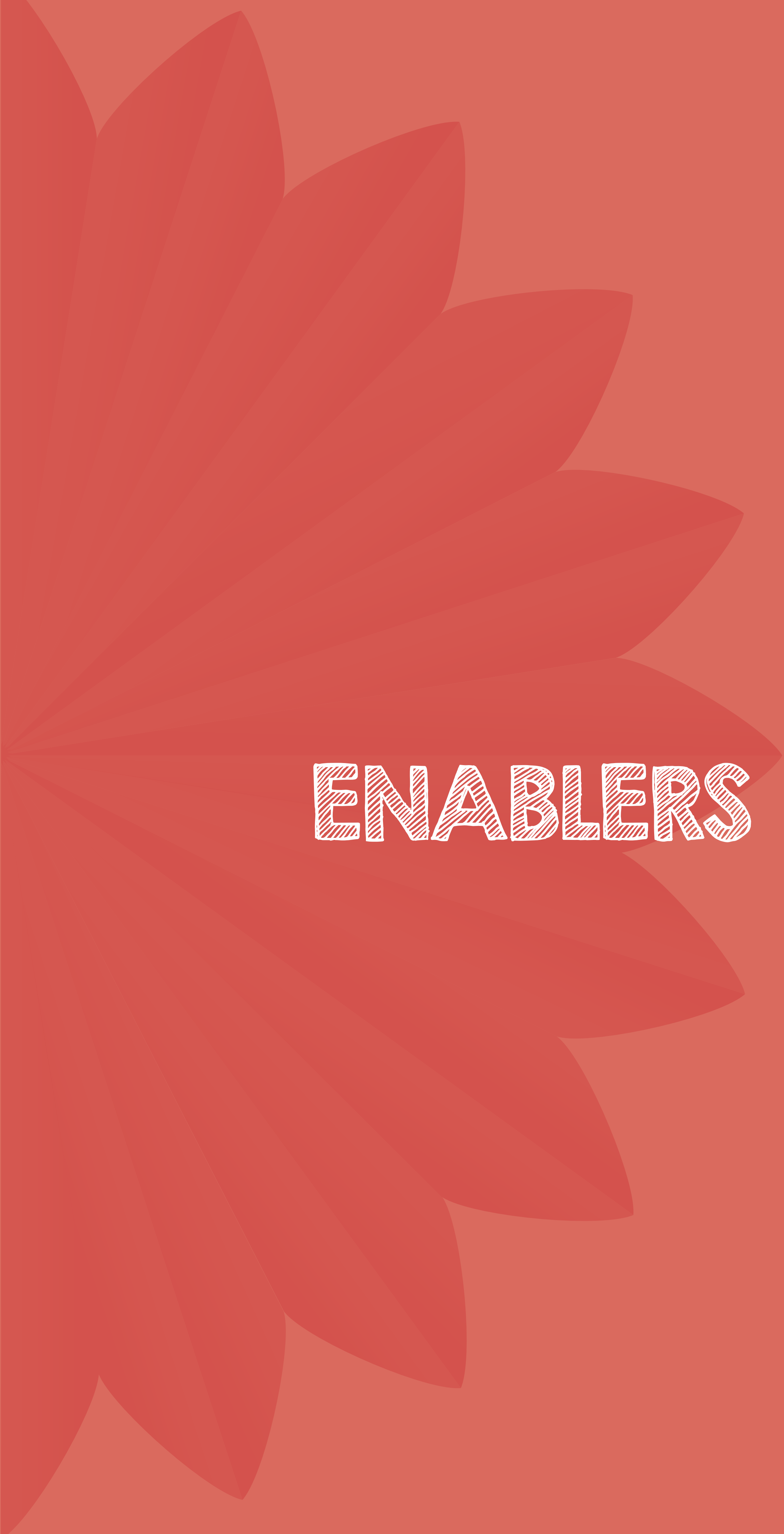
- Evaluate and further develop a range of culturally appropriate prevention, management and support models for Indigenous people and their communities building on successful programs operating around Australia.
- Evaluate, promote and further develop prevention, management and support models for alcohol dependent women and women with FASD themselves.
- Provide FASD screening, management and post release referral services to young people in detention centres (sentenced and on remand) and in community programs servicing young offenders.

Objective: Work with the criminal justice system to implement therapeutic justice interventions

Activities that could contribute to the objective

- Provide FASD education and training to staff in juvenile justice systems, and community policing, including identification processes and referral pathways for further assessment and support.
- Ensure individuals suspected of developmental or cognitive impairment have access to appropriate case management, including through the appointment of specialist court-based clinicians and access to diversionary programs in Indigenous communities. This will involve community-controlled processes 'on-country' and will provide a culturally secure and appropriate environment for stabilising children with FASD.
- Expand non-custodial therapeutic options to ensure that courts can divert offenders identified with neurodevelopmental or cognitive impairments, including FASD, away from prisons and into programs and services.

ENABLERS



Enablers

Recognise FASD

FASD is under-recognised, and this represents a substantial barrier to early detection, diagnosis, support and assistance that prevents significant improvement of outcomes for individuals and their families.

There are a number of organisations and resources which aim to increase the understanding of FASD and to improve the lived experience and life outcomes of individuals with FASD and their families.

The Plan supports the ongoing need for these activities while recognising that better coordination across all sectors, including health, education, employment, criminal justice and a broad range of other community services, is fundamental to improving life outcomes for people living with FASD.

Activities that could support the enabler

- Promote shared responsibility for the prevention and management of FASD by establishing a mechanism for regular dialogue across Commonwealth agencies, state and territory governments and the non-government sector.
- Review legislation and policies at Commonwealth, state and territory and local government levels to determine if FASD is appropriately recognised as a disability to enable appropriate support to be provided through key health, community and disability support programs.
- Implement a comprehensive range of strategies to prevent and reduce alcohol-related harm, including FASD, through the NAS.

Eliminate stigma

Despite a broad range of efforts to date, there is still a lack of public understanding about FASD. Media portrayals and community attitudes can result in stigma. Consequently those affected by FASD (including children diagnosed with FASD and their mothers and families) may feel shamed and blamed.

Stigma can also influence the prevention and identification of FASD. Inadvertent stigmatising by public health FASD initiatives can limit the willingness of those affected by FASD to seek information, care, support and assistance.[56]

Efforts to prevent and eliminate stigma must continue to be embedded across all activities. This requires careful consideration to the nature of any messaging – tone of voice and language, employing women-centred and compassionate support for all pregnant women, and avoiding stories which blame or shame mothers of children with FASD.

Community and public education should embed the message that everyone has responsibility for prevention of alcohol-exposed pregnancies, not just women themselves. All approaches to dealing with alcohol consumption during pregnancy must consider the range of socio-economic needs and pressures which affect women's behaviours. In particular, services for pregnant women who are alcohol dependent or have problematic alcohol use must be provided by trained specialists in a compassionate and sensitive manner.

The success of other destigmatising health campaigns, particularly mental health campaigns to address myths and tackle stigma, can provide useful lessons for FASD anti-stigma strategies going forward.[57]

Activities that could support the enabler

- Embed an approach which prevents and aims to eliminate stigma in all elements of FASD policy and programs.
- Ensure FASD public education and awareness raising campaigns focus on:
    - de-normalising drinking behaviour rather than stigmatising the individual;
    - promoting an understanding of the condition;
    - being non-judgemental;
    - not placing blame on mothers; and
    - focusing on narratives of success with those living with FASD.
- Encourage the media to develop guidelines for responsible reporting to reduce inaccurate or misleading messages related to alcohol use during pregnancy and encourage the non-stigmatising portrayal of people with FASD.
- Provide health warnings that are legible, easily understood and meaningful on alcohol use in pregnancy on all alcohol containers sold in Australia and in venues where non-packaged liquor is sold and consumed.

Education and Training

The Plan recognises that efforts to equip health and community service professionals with adequate knowledge and confidence to diagnose, support and manage those with FASD are needed to ensure that mothers at risk and children affected are not missed. These activities are fundamental to support early detection and care. This is crucial to limit secondary disabilities, and preventing a sibling being born with FASD. [58] [59]

Professionals working in health, education and justice and other areas of community service delivery can play an important role in recognising, screening and assisting people with FASD. Tailored education and awareness programs will assist capacity across all sectors to address the levels of unmet need arising from FASD and contribute to more positive outcomes throughout the lifespan for those living with FASD.

Activities that could support the enabler

- Continue to expand the range and type of FASD resources for all sectors.
- Employment and training of workers seeking to prevent alcohol-related harm within communities, including community action to reduce alcohol use in pregnancy.
- Train officers in the justice system to identify children suspected of being affected by FASD and initiating referral for further screening and assessment.
- Integrate specific education approaches into teacher training to provide better in-class support for children with FASD.
- Train domestic violence workers in recognition of FASD as a cause and contributor.
- Deliver education and training to enable a broad range of health and community workers to ask women about alcohol consumption and provide advice and referral to appropriate services.
- Equip primary care workers and Aboriginal health workers with the skills and training needed to contribute to FASD identification and management.

Policy Coordination

This Plan recognises that coordination and collaboration across jurisdictions and communities is essential to achieving its aim to reduce the prevalence of FASD and the impact it has on individuals, families, carers and communities.

Activities that could support the enabler

- Ensure collaboration between all levels of government and sectors on implementation of evidence-based initiatives.

Frontline Health and Human Service Professionals

Activities that could support the enabler

- Ensure that all health and human service education at under-graduate and post-graduate levels and in continuing professional development courses include core competencies in the prevention, screening, diagnosis and management of FASD.

Schools and teachers

Activities that could support the enabler

- Implement education and training programs to support school teachers to recognise, manage and teach students with FASD.
- Build on successful programs that have developed practical education resources to support school leaders, teachers, Aboriginal educators and the broader school community to understand and work effectively with school students living with FASD.

Legal system

Activities that could support the enabler

- Implement education and training for professionals in the juvenile and adult justice system, including probation workers, through-care case workers, social workers, education professionals, police officers, detention workers, and staff in group homes, correctional facilities, shelter homes, and mental health facilities, to recognise FASD and assist individuals to access the support and assistance they need to navigate the systems and improve life outcomes.
- Review interview practices by creating a guide for investigations to ensure interview fairness and voluntariness when an officer or other justice department member interviews a person exhibiting developmental or cognitive impairement.

Research and evaluation

There are a number of gaps in data and research in Australia in relation to key dimensions of FASD.

The CRE funded by the NHMRC from 2016-2020 will focus on additional research and strategies to prevent alcohol use in pregnancy and improve national FASD diagnostic capacity and management through effective interventions. However, literature on FASD and consultations undertaken during the development of the Action Plan identified a broad range of priorities for FASD research and evaluation.

Research to accurately determine the prevalence and incidence of FASD in Australia was also identified as an important tool to inform development of policies and programs. Continuing national surveillance and maintaining a register to monitor trends and outcomes of FASD and focusing on diagnosing and treating children in at-risk groups was also identified as a priority.

The lack of a rigorous evidence-base to identify the efficiency and effectiveness of pharmacological and wide ranging non-pharmacological interventions was also highlighted as requiring action. Suggestions for further action include the use of randomised controlled trials and with adequate sample sizes.

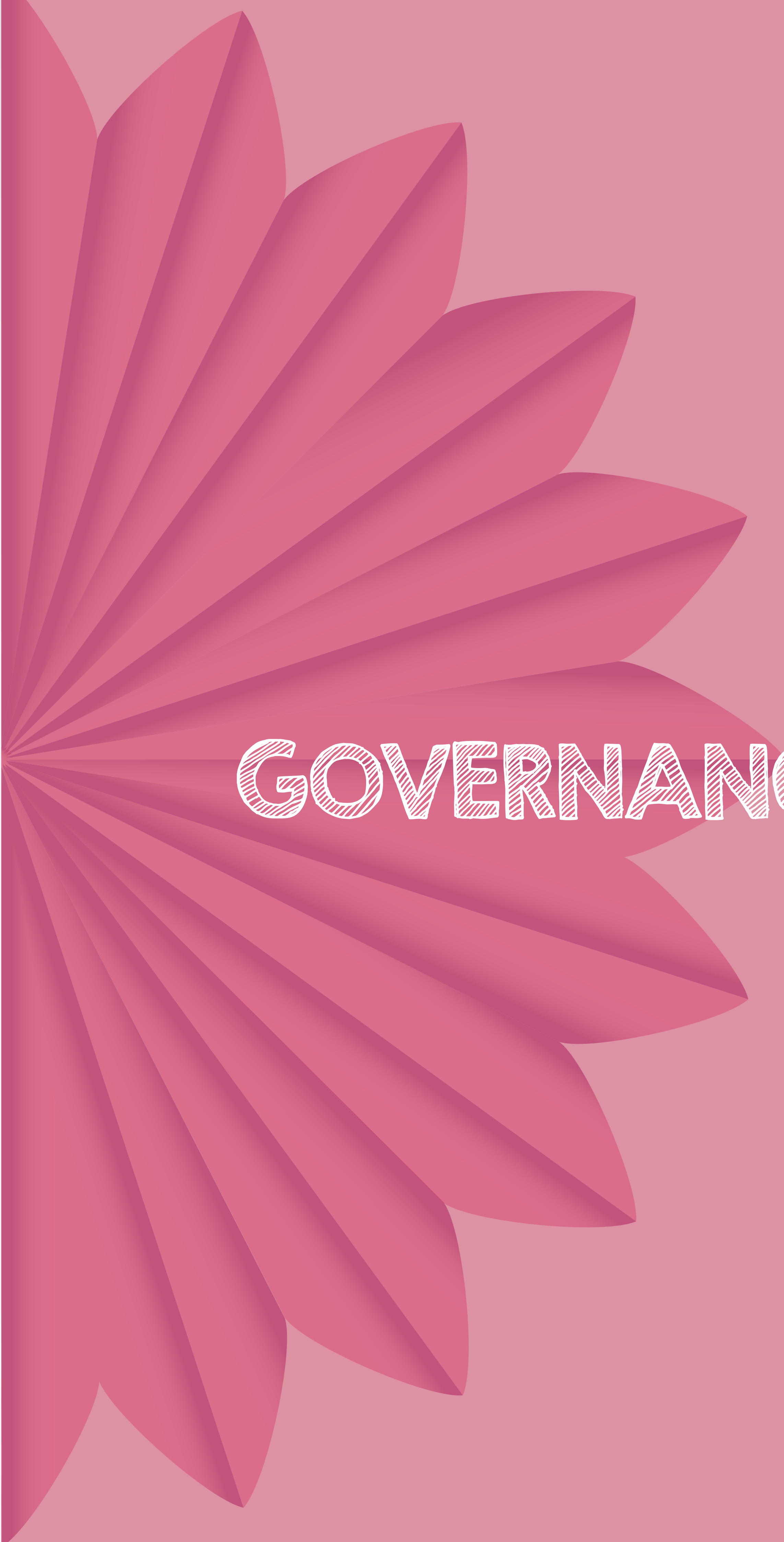
Research is also needed to: understand patterns of service use and characteristics of the FASD population; ascertain if FASD is an issue in culturally and linguistically diverse (CALD) population groups; develop outcome measures which allow assessment of how improvements result from various models of preventing alcohol use in pregnancy and related harm; the management of FASD for individuals over their lifetime; test new diagnostic techniques and evaluate novel therapies; and to determine the costs associated with identification, management and support of individuals with FASD, their families and carers.

The need for more training and education for health and other key community service providers has been identified under the Plan. While many education and training resources have been produced for front-line professionals, research to evaluate the dissemination, uptake, appropriateness and benefits should be undertaken.

Activities that could support the enabler

- Support of further epidemiological research to better understand prevalence rates, particularly in at-risk groups.
- Build the availability of data on alcohol consumption during pregnancy to better monitor progress in reducing maternal alcohol consumption through improving data collections.
- Amend data collections to collect country of birth and language spoken at home information.
- Support the continuation of national FASD surveillance and the national FASD Register as tools that enable collection of epidemiological data and monitoring of prevalence trends and prognosis.
- Support systems-based research to prevent risky alcohol use and related harm, including FASD.
- Prioritise translational and implementation research to drive adoption of FASD diagnostic guidelines, diagnostic activity and therapy support models.
- Evaluate the effectiveness of new therapies and novel diagnostics, such as 3D facial imaging, epigenetics, genetics, eye movements and biomarkers.
- Review the *Australian Guide to the Diagnosis of FASD* and associated training.
- Conduct health economic modelling of FASD to assess the full costs and the value to Australian society and the community if FASD was adequately identified, managed and prevented.
- Build opportunities for policy development and evaluation and reporting of progress to be informed by those with lived experience and outcome measurements where possible.

GOVERNANCE



Governance

As is the case for broader policy issues relating to alcohol-related harm, responsibility for responding to the priorities and objectives identified and outlined through the Plan is shared between the Commonwealth and state and territory governments.

As a supplementary document to the National Alcohol Strategy (itself a sub-strategy of the National Drug Strategy), the Plan is formally overseen by the Ministerial Drug and Alcohol Forum (MDAF) which is supported by the National Drug Strategy Committee (NDSC).

However, monitoring the progress and supporting the Plan is not solely the responsibility of government bodies - nor are the activities identified the sole responsibility of Ministers who participate in the MDAF or portfolios who constitute the NDSC.

Indeed the priorities, objectives and opportunities have been informed by a wide range of stakeholders, including families, advocacy and support groups, clinicians, community-based organisations, non-government organisations, individuals and researchers from different backgrounds, sectors and perspectives.

It is critical that those who helped to shape the Plan are also represented in monitoring and reporting on its progress. As such, the NDSC will establish an ongoing National FASD Advisory Group (the FASD Advisory Group) to take on this role.

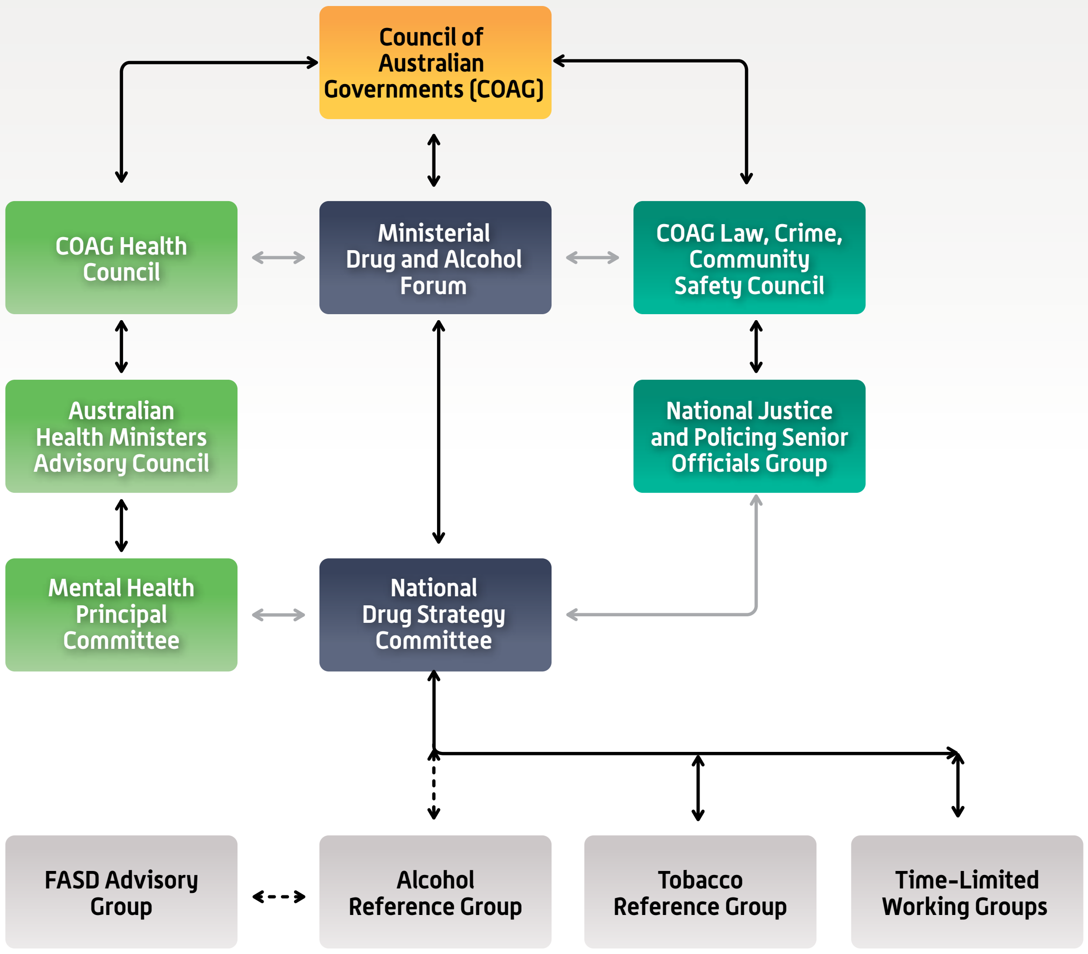
While the Terms of Reference and inaugural membership of the FASD Advisory Group will be developed by the NDSC and confirmed by the MDAF, it is expected that it will:

- include membership with differing expertise and/or lived experience with government and non-government representation;
- be co-chaired by a representative of the Commonwealth Department of Health and a non-government representative;
- report through the National Alcohol Strategy Expert Reference Group (to be established);
- be responsible for oversight and reporting under the monitoring and evaluation framework outlined in this Plan (including the mid-point review); and
- provide advice on emerging issues, trends, opportunities and gaps that may exist across the domains of the Plan.

The final Terms of Reference and membership of the FASD Advisory Group will be published on the MDAF website. The updated governance arrangements are depicted in the diagram on the following page.

It is also important to ensure that appropriate links are drawn between the MDAF and other relevant COAG structures to ensure whole-of-government consideration of this Plan is maintained.

COAG Alcohol and other Drugs Governance Model



🟩 Health only

🟩 Law Enforcement and Justice only

⬛ Cross-Sectional (Health, Law Enforcement/Justice)

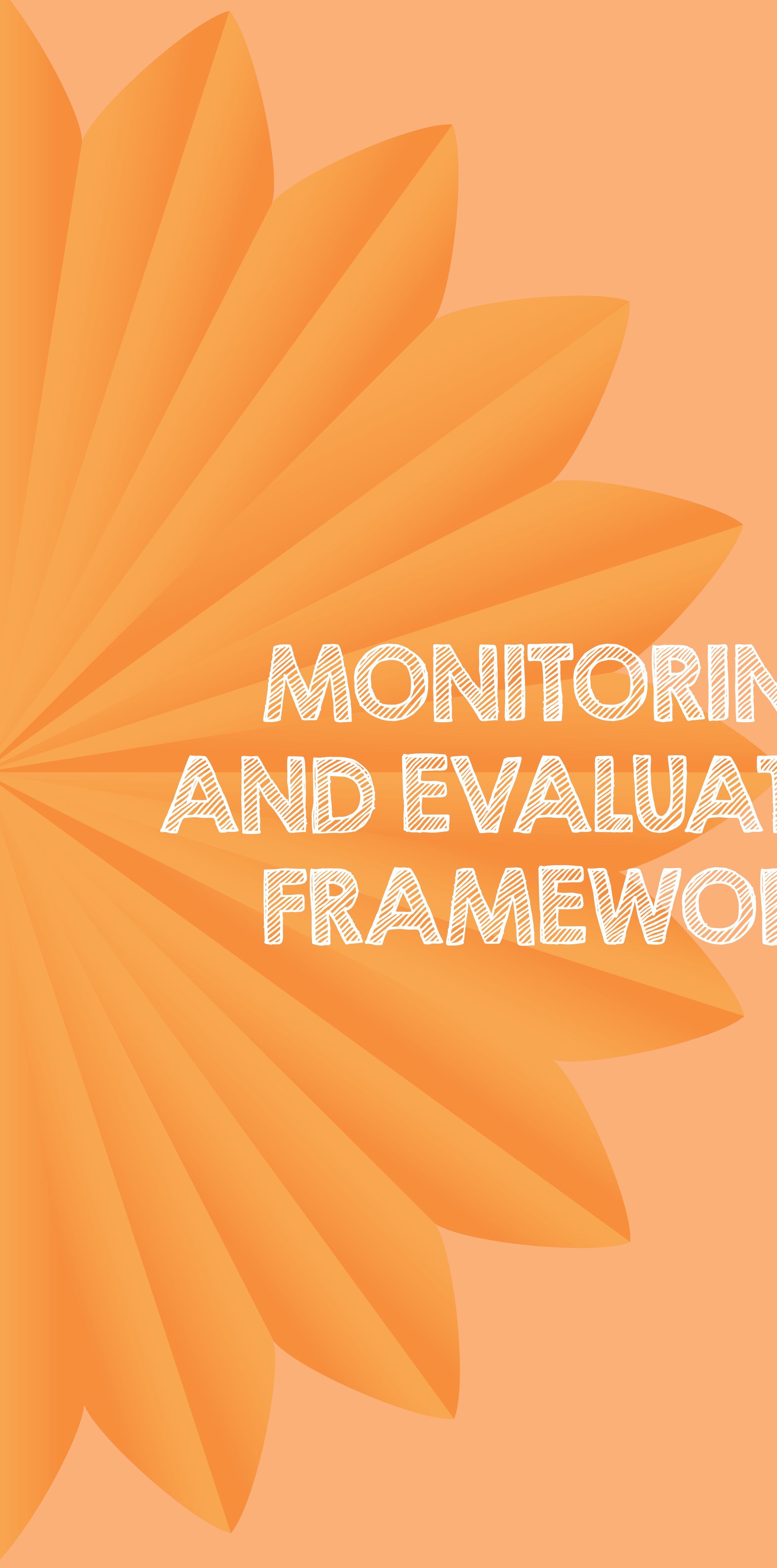
⬜ NDSC Sub-Groups

⟷ Formal Reporting Line

⟷ Informative Exchange/Exchange Pathway

<--> Proposed Reporting Line

MONITORING AND EVALUATION FRAMEWORK



Monitoring and evaluation framework

The Plan provides Australia with guidance on opportunities which can contribute to the prevention, diagnosis, support and management of FASD over a ten year period to 2028.

The purpose of this monitoring and evaluation framework is to provide guidance to the FASD Advisory Group on how to monitor progress of the Plan at national, state and territory and local levels. Additionally, the framework will provide strategies for improvement in line with best practice research.

The evaluation framework therefore, needs to include ways to assess whether or not the Plan was ultimately useful to all stakeholders.

This monitoring and evaluation framework assumes that, in line with good practice, all activities influenced by the Plan will have appropriate levels of evaluation.

Proposed timeframe for monitoring and evaluation activities

Monitoring will be continuous throughout the lifespan of the Plan. There is an expectation that it will be formally reviewed after a 3 year period, at the mid-point and its ninth year of implementation. It is anticipated that the formal periodic reviews will be undertaken against the questions provided in this document and considered by and potentially revised by MDAF through NDSC.

Evaluation questions

The complexity of the inter-relationships and inter-dependencies within the Plan require an approach to monitoring and evaluation that:

- builds as much as possible on existing data sources;
- relies on the availability of evaluations of individual initiatives across sectors;
- draws on expert opinion as well as evidence, and ultimately triangulates qualitative and quantitative data from many different sources; and
- links with research and evaluation structures such as NHMRC-funded Centres of Research Excellence and partnership grants.

Development of the evaluation framework identified the following categories of evaluation questions. Those that:

- answer specific questions about FASD activity and sit within the Plan; and
- seek to answer if the Plan has delivered on its purpose of guiding prevention, diagnosis, support and management of FASD in Australia.

Implementation of proposed activities within the Plan will over time address the gaps in available data for assessing outputs and outcomes. They are not available at the time of drafting this framework.

Likewise, while there is a reasonable evidence-base for various activities suggested in the Plan, many are innovative and have not yet been adequately evaluated. It is intended that there will be a mid-point review of the Plan, to which the individual program evaluations and evidence-base will contribute.

The table on the following pages sets out questions against which the Plan may be assessed including possible data sources which could be used to answer the questions.

Table 1: Evaluation Questions for the National Priority Areas

About the Strategic Action Plan		
Effect of the Strategic Action Plan nationally, and at state and territory and local levels		
Evaluation questions	**Methodologies**	**Sources**
1. To what extent has the Strategic Action Plan been implemented in a way that aligns with the National Alcohol Strategy Priority Areas? **1.1** Are there any of the Priority Areas that require additional focus? **1.2** Are there any changes in external factors outside the scope of the Strategic Action Plan that have enabled or limited the capacity to implement the Strategic Action Plan?	Monitoring Commonwealth, state and territory and NGO activity against the Priority Areas and objectives of the Strategic Action Plan Expert and stakeholder consultation	Document review Key informant, stakeholder and expert interviews Evaluation reports at the initiative level
2. To what extent has the Strategic Action Plan been used by key stakeholders in the Commonwealth government, state and territory governments and the non-government organisations? What, if any, legislative and policy changes have emerged as a result of the Strategic Action Plan, e.g. in relation to recognising FASD as a disability? **2.1** Has the Strategic Action Plan effectively promoted shared responsibility for the prevention and management of FASD between Commonwealth agencies, state and territory governments and the non-government sector? **2.2** Has the Strategic Action Plan contributed to the development of national, state and territory and local initiatives to eliminate or reduce stigma experienced by people living with FASD and their families?		
3. Is there evidence that public education and awareness raising campaigns are aligned with the advice contained in the Strategic Action Plan that focus on raising awareness about the risk of drinking in pregnancy and FASD, belief that not drinking is the safest choice and intention to not drink whilst pregnant; and increase support for women not drinking in pregnancy while minimising stigmatising the individual?		

4. Has the national Strategic Action Plan supported or influenced: ● improved data on prevalence ● evaluation of new therapies and novel diagnostics ● improved outcome measurement for individuals with FASD and their families ● evaluation of FASD guidelines and tools targeting professionals ● the conduct of health economic modelling of the impact of FASD ● new interventions for prevention and management of FASD	Meta-evaluation of existing evaluations of public education and awareness raising campaigns Analysis of reports of research funding bodies Literature and document review	Annual reports of Commonwealth, state and territory governments Commonwealth, state and territory strategies and action plans Research strategy documents Epidemiological, clinical and health services research
5. For all questions above: **5.1** Are there differences for different demographics or population groups? **5.2** What factors or elements are influencing the opportunities for action specified in the Strategic Action Plan?		

Table 2: Evaluation Questions for the National Priority Areas

Prevention

Objective: Reduce access and consumption of alcohol in the Australian community

Evaluation questions	Methodologies	Sources
1.1 To what extent has there been a change in pricing and promotion, reduction to access and consumption of alcohol? **1.2** To what extent have Commonwealth, state and territory efforts supported at-risk population groups to implement culturally appropriate initiatives to reduce access to and consumption of alcohol.	Review of legislative arrangements Assessment of implementation of evidence based population-wide, local-at-risk population restrictions	Relevant Commonwealth, state and territory alcohol legislation and initiatives

Objective: Increase community knowledge and awareness about the harms and consequences of drinking in pregnancy

Evaluation questions	Methodologies	Sources
2.1 To what extent have evidence-based public education campaigns about the harms and consequences of drinking during pregnancy been implemented? **2.2** To what extent have evidence-based public education campaigns for high risks groups been implemented and evaluated?	Assessment of the number and nature of public education campaigns designed and implemented in line with good practice Assessment of the number and nature of evidence-based public education campaigns targeting high risk groups including those which engage both women and their partners, are culturally sensitive, are informed by community knowledge, attitudes, values and drinking practices and are fully consistent with national guidelines Expert and stakeholder consultation	Expert key informants

Screening and diagnosis

Objective: Increase screening and diagnostic skills and knowledge in frontline professionals

Evaluation questions	Methodologies	Sources
1.1 To what extent have opportunities to improve access to appropriate and evidence-based diagnosis and support services through existing programs been maximised? **1.2** What coverage of the health and human services workforce has been achieved by training and development efforts? **1.3** How effective have efforts to disseminate and train medical and health professionals in the Australian Guide to the Diagnosis of FASD and the Australian FASD Diagnostic Tool and Referral Guidelines been? **1.4** To what extent has the general training for assessing child development in a range of health care settings alerted practitioners to the need to identify all forms of neurodevelopment impairment including FASD?	Monitoring of program responses to FASD Expert and stakeholder consultation Surveys of health workforce development/ education and training providers Surveys of early childhood workforce	Document review Expert key informants Stakeholders in child development across sectors (e.g. health, child protection, corrections) Survey results

Objective: Improve capacity for screening, diagnosis and surveillance

Evaluation questions	Methodologies	Sources
2.1 To what extent has the FASD pre-screening tool been developed for widespread use? **2.2** Have best practice models been developed and disseminated to child health nurses, child and family services to support their capacity to contribute to the FASD diagnostic process in their service setting? **2.3** How successful have efforts to improve the coverage and quality of the FASD Australian Register been?	Evaluation of projects commissioned to design and disseminate best practice Analysis of the coverage and quality of the data in the register Expert key informant interviews	Document review FASD Australian Register data Expert key informants

Support and management

Objective: Implement and evaluate better models of management, support and care

Evaluation questions	Methodologies	Sources
1.1 To what extent has the national Strategic Action Plan influenced the development and evaluation of evidenced-based multidisciplinary models of care across the lifespan and which align with principles of good practice noted in the Strategic Action Plan? **1.2** To what extent are the models of care used where there is a high prevalence of FASD and limited access to services? **1.3** To what extent have mental health and drug and alcohol services adopted the routine consideration of FASD in their diagnostic and management plans and interventions? **1.4** To what extent are Commonwealth, state and territory and local government legislation and policy influenced by the national Strategic Action Plan to appropriately recognise FASD as a disability, and improve the extent to which individuals' and their families' needs are met?	Systematic review (and meta-analysis if appropriate) of evaluations of models of care Survey of alcohol and other drug providers Expert key informant interviews Stakeholder consultation	Document review Commonwealth, state and territory strategies and action plans Reports of evaluations of models of care Expert informants Consumer and carer stakeholders Surveys of providers Survey results

Objective: Support for parents, carers and families and in schools			
	Evaluation questions	**Methodologies**	**Sources**
2.1	To what extent have FASD resources been expanded for individuals, their families and carers including information about the diversity of support services available (e.g. suicide prevention programs, sporting programs, peer and family support groups, parent training programs, vocational and training services)?	Review and mapping of resources and their coverage of agreed key topics	Monitoring and evaluation reports of FASD Hub and NOFASD Commonwealth, state and territory annual reports Stakeholders and expert informants
2.2	To what extent are children with FASD receiving specialised school programs to address their particular needs including education and training for teachers about FASD, evidence-based classroom strategies and involvement in the delivery of individualised education plans (IEP)?	Review and mapping of the availability of specialised school programs	
2.3	To what extent are supportive services for pregnant women and their partners more accessible including brief intervention for alcohol use in pregnancy, contraception and reproductive technology options and specialised treatment for pregnant women who are alcohol dependent?	Review and mapping of education and training for teachers about FASD, classroom strategies and use of IEPs	

Priority groups

Objective: Continue to support and evaluate targeted strategies and models of care for groups within the Australian community who are at higher risk than the general population

Evaluation questions	Methodologies	Sources
1.1 To what extent are Indigenous communities supported to evaluate and further develop a range of culturally appropriate prevention, treatment and support programs? **1.2** To what extent are young people in detention centres and community programs for young offenders screened for FASD, offered post release referral services and offered treatment?	Consultation with Aboriginal and Torres Strait Islander peak bodies and community-controlled health services Review of program design and evaluation reports Expert informant consultations Stakeholder consultations	Commonwealth, state and territory judicial reports Expert informants Community stakeholders

2.1 To what extent are staff in juvenile justice systems provided FASD education and training including identification processes and referral pathways for further assessment and support? **2.2** To what extent are individuals suspected of developmental or cognitive impairment accessing appropriate case management, including through the appointment of specialist court-based clinicians and access to diversionary programs in Indigenous communities which involve community-controlled processes 'on-country' and provide culturally secure and appropriate environment for stabilising children with FASD? **2.3** To what extent are non-custodial therapeutic options used by courts to divert FASD-affected offenders away from prisons and into programs and services?	Monitoring education and training opportunities in juvenile justice system Review of Commonwealth, state and territory legislation, policy and program development Expert and stakeholder consultations Mapping of court-based clinical and diversionary programs	Document review Expert and community stakeholders Commonwealth, state and territory judicial reports

USEFUL RESOURCES

FASD Hub

The FASD Hub is a one-stop shop for all information, tools, resources, research and consumer support about FASD in Australia.

The Hub is a repository for clinically accurate information, diagnostic tools, referral services, research and consumer information.

fasdhub.org.au

Pregnant Pause

The 'Pregnant Pause' campaign encourages Australians to go alcohol free during their pregnancy, or the pregnancy of their partner, family member, friend or loved one.

pregnantpause.com.au

Australian Guide to the diagnosis of FASD

The Australian Guide to the Diagnosis of FASD was produced to assist clinicians in the diagnosis, referral and managementof Fetal Alcohol Spectrum Disorder.

It contains the Australian Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Instrument and information about how to use the instrument.

https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/guide-to-diagnosis/

NOFASD Australia

National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) Australia's mission is to provide a strong and effective voice for individuals and families living with FASD, while supporting initiatives across Australia to promote prevention, diagnosis, intervention and management.

nofasd.org.au

Women Want to Know

The 'Women Want to Know' project encourages health professionals to routinely discuss alcohol and pregnancy with women and to provide advice that is consistent with the Australian Guidelines to Reduce Health Risks from Drinking Alcohol.

http://alcohol.gov.au/internet/alcohol/publishing.nsf/Content/wwtk

AUDIT-C

One way to assess a woman's alcohol consumption is by using the AUDIT-C (Alcohol Use Disorders Identification Test – Consumption).

This tool has three short questions that estimate alcohol consumption in a standard, meaningful and non-judgemental manner.

alcohol.gov.au/internet/alcohol/publishing.nsf/Content/wwtk-audit-c

AOD Knowledge Centre

The Alcohol and Other Drugs Knowledge Centre was established by the Australian Indigenous *HealthInfoNet* in partnership with the National Drug Research Institute, the National Drug and Alcohol Research Centre and the National Centre for Education Training on Addiction.

aodknowledgecentre.ecu.edu.au/about/

FASD in Australia: An update

Monograph of the Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders

nationaldrugstrategy.gov.au/internet/drugstrategy/publishing.nsf/Content/mono-fasd

Substance use in pregnancy resource project

The National Drug and Alcohol Research Centre was engaged to develop a resource for the identification, management and, if appropriate, referral of women who are pregnant and have a substance misuse problem.

ndarc.med.unsw.edu.au/project/substance-use-pregnancy-resource-development-project

Australian Guidelines to Reduce Health Risks from Drinking Alcohol

NHMRC's Australian Guidelines to Reduce Health Risks from Drinking Alcohol 2009 (2009 Alcohol Guidelines) aim to provide health professionals, policy makers and the Australian community with evidence-based advice on the health effects of drinking alcohol.

nhmrc.gov.au/health-topics/alcohol-guidelines

Understanding and addressing the needs of children and young people living with FASD – A resource for teachers

This practical education resource is designed to support school leaders, teachers, Aboriginal educators and the broader school community to recognise, understand and work effectively with students living with FASD in schools.

kimberleyfasdresource.com.au/pdf/FASD_ResourceForTeachers.pdf

Endnotes

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