Government of **Western Australia**
Department of **Health**

Delivering a **Healthy WA**

House of Representatives Inquiry into Fetal Alcohol Spectrum Disorder:

WA Health, Health Networks Branch (Child and Youth Health Network) Response

Background
Foetal Alcohol Spectrum Disorder (FASD) is an overarching term used to describe a range of cognitive, physical, mental, behavioural, learning and developmental disorders that result from fetal exposure to alcohol.

The Standing Committee on Social Policy and Legal Affairs is to inquire into and report on developing a national approach to the prevention, intervention and management of FASD in Australia, with particular reference to:

- **Prevention strategies –** including education campaigns and consideration of options such as product warnings and other mechanisms to raise awareness of the harmful nature of alcohol consumption during pregnancy,
- **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, and
- **Management issues –** including access to appropriate community care and support services across education, health, community services, employment and criminal justice sectors for the communities, families and individuals impacted by FASD.

WA Health
WA Health welcomes this Standing Committee inquiry and a National approach to addressing FASD. From a WA Health perspective, the focus of any National approach should be that while there is no cure for FASD, it is an entirely preventable condition. In particular, WA Health recommends that this approach prioritises a whole of government response with a focus on prevention and takes into consideration the circumstances of each state and can be flexible to the needs of different communities at the local level. Through implementing an across government, National response, WA Health hopes this will result in a National approach to service delivery and positive health outcomes. While WA Health is working within current budgets to lead the implementation of the 33 FASD Model of Care recommendations, access to additional funding through Federal & other sources will be required to ensure a consistent and equitable approach across all jurisdictions.

The following issues outlined below illustrate the current context of FASD:

- Alcohol is widely used and accepted as part of Australia's society and culture.
- Alcohol consumption during pregnancy needs to be viewed within the wider context of community attitudes to drinking.
- WA research has shown that around 50 % of live births are unplanned; therefore many pregnancies may be exposed to alcohol before the women realizes they are pregnant.
- There is a lack of reliable prevalence data for FASD in Australia, therefore the full cost and prevalence of the condition is unknown.
- There is no screening system in place for women of child-bearing age who are pregnant or planning a pregnancy.
- There is no coordinated service to diagnose children with FASD or to provide ongoing services.

In order to appropriately address FASD a coordinated and consistent whole of government approach across National and State governments is required and must be based on quality research and where available, evidence based best practice. Strategies and services should be delivered across the whole continuum of care but with an emphasis on primary, secondary and tertiary prevention. FASD is an entirely preventable condition and it is encouraging that there are a number of people who are committed to working in this area. Throughout the past year significant work around the management and prevention of FASD at State and National levels has included:

- Work of the National Preventative Taskforce, of which alcohol is one of the of three priority areas.
- National Monograph –Fetal Alcohol Spectrum Disorder in Australia: An update.
- WA Parliamentary inquiry by the Education and Health Standing Committee.
- WA Community Services Leadership Group (committee of Director Generals from human and health service Government Departments) endorsement to participate in a whole of government approach to the implementation of the FASD Model of Care.
- Key research projects by the National Health and Medical Research Council and the Telethon Institute for Child Health Research.

The FASD Model of Care

In 2010 the WA Child and Youth Health Network published the FASD Model of Care following participation and consultation from a working group comprising of expertise from various government and non-government agencies. The FASD Model of Care is evidenced based and describes the continuum of care, including the prevention, diagnosis, and treatment/management of FASD and 33 recommendations for implementation.

Objectives of the model of care are to:

- Prioritise the use of prevention strategies to reduce the prevalence of FASD, recognising there is no cure for this avoidable condition.
- Implement appropriate screening programs to prevent FASD.
- Provide early intervention for pregnant women with alcohol problems and children diagnosed with FASD.
- Develop a multi-disciplinary FASD diagnostic service for children within the Child Development Service.
- Develop clinical pathways for joint FASD assessment with other relevant health services and agencies.
- Encourage collaboration of specialised service for children diagnosed with FASD.
- Support an inter-agency approach to prevention, diagnosis and management of FASD.
- Ensure training and education on FASD is available to all relevant health professionals at multiple levels including under-graduate, post-graduate and in-service training programs.
- Develop approved channels of agreed and confidential communication between sectors for any child diagnosed with FASD.
- Facilitate data linkage ability between sectors.
- Undertake further research to more accurately determine the prevalence of FASD in specific communities/regions.

It can be accessed from: http://www.healthnetworks.health.wa.gov.au/modelsofcare/docs/FASD_Model_of_Care.pdf

WA Health Working towards Implementation of the Model of Care

WA Health is currently working towards the implementation of the FASD Model of Care. The 33 recommendations outlined in the Model align closely with the 10 recommendations described in the Monograph and range across the continuum of care from primary prevention through to diagnosis, secondary prevention, early intervention, screening, treatment and management of those living with FASD. WA Health has the support from multiple health and human service government departments to establish intersectoral working groups and develop strategies to implement the 33 recommendations outlined in the Model, particularly with an emphasis on primary prevention, diagnosis and secondary prevention. This process is overseen by a Project Control Group led by WA Health and consisting of representatives from the Drug and Alcohol Office, Department of Education and Department for Communities.

Addressing the Terms of Reference

The table below outlines the strategies WA Health are working towards implementing, as recommended in the FASD Model of Care as well as projects currently being undertaken which link to the three items identified in the Inquiry Terms of Reference.

	WA Health's position	**Specific projects**
Prevention Strategies		
e.g. education campaigns, product warnings & awareness raising mechanisms.	• FASD is 100% preventable; prevention is the core aim of the FASD Model of Care (MoC) & Implementation Plans. • A holistic approach is required –health professionals & policy makers addressing the issue of alcohol & women's health/pregnancy should consider other health, psychosocial, cultural, regulatory & economic factors. Key prevention recommendations and strategies are outlined below: • Primary Prevention: o Public awareness and policy change to reduce harmful drinking across the population, particularly those at child bearing age and risk of unplanned pregnancies. o Include interventions to change individual behaviours, the community attitudes & systems that support the current drinking culture & environments influencing how people consume alcohol. o Promote abstinence from alcohol and other healthy behaviour practices for pre-conception & pregnancy. • Secondary Prevention: o Reduce the risk of alcohol-related harm to the fetus through preventing/minimising alcohol consumption during pregnancy; screening pregnant women for alcohol consumption & identifying/intervening with women who have harmful patterns of alcohol consumption. o Improving access to antenatal & maternity services for disadvantaged groups. o Providing information to all pregnant women/families about substance use & risk associated with alcohol use during pregnancy. o Promote abstinence from alcohol during pregnancy.	<u>State-wide awareness raising campaign</u> Through funding from COAG Closing the Gap, the Drug and Alcohol Office (DAO) have rolled out a state-wide awareness raising campaign, targeting Aboriginal people, around risks of alcohol and pregnancy. This campaign also involved workforce development initiatives for FASD prevention, particularly targeted at to frontline health practitioners and AOD (alcohol and other drug) workers. <u>State-wide education resources</u> DAO have also partnered with the Telethon Institute of Child Health Research to develop state-wide resources (originally funded through Healthway) to educate health workers,

	o Establish protocols for brief interventions addressing maternal alcohol use during pregnancy. o Increase collaboration between all health professionals & alcohol/other drug services to ensure comprehensive drug/alcohol maternity services for all pregnant women, including those in rural & remote regions. • Tertiary Prevention: o Target women who have a child with FASD &/or with alcohol-related dependency. o Identify gaps in the provision of antenatal care for women with alcohol-related dependency. o Screen for & manage alcohol withdrawal for pregnant women. o Refer pregnant/post-partum women with alcohol-related dependency to comprehensive health services addressing parenting & child/family well-being. • In order to successfully implement the above prevention recommendations, the following supports are required: o Incorporation of relevant recommendations into policies, procedures & guidelines; practice guidelines; and professional development - capacity & competencies. o Education & training programs for health professionals. o Education of key stakeholders about the issue of FASD and prevention strategies relevant to their profession. o Provision of alcohol & pregnancy resources for health professionals, women & the community. o Monitoring & evaluation of implementation of policy, programs, outcomes & the effectiveness of strategies.	men & women around alcohol use during pregnancy and breast feeding.
Intervention Needs		
e.g. FASD diagnostic tools & early intervention therapies.	• There is currently no single internationally accepted classification system for FASD. The MOC recommends development of a multi-disciplinary FASD diagnostic service for children within the Child Development Service & development of clinical pathways for joint FAS assessment with other relevant health services & agencies.	<u>Screening/Diagnostic instrument</u> Partnerships with the Telethon Institute for Child Health Research (TICHR) – development of a

	• Universal screening & data collection on alcohol consumption during pregnancy is also recommended.
	• Appropriate screening programs will provide opportunities to prevent FASD & provide early intervention for pregnant women with alcohol problems & children diagnosed with FASD.
	• Screening activity should occur during the following milestones:
	  o women during pregnancy;
	  o newborns; and
	  o during early childhood or at enrolment in full time education (4-6 years).
	• The MOC identifies a number of sub-population groups at high risk of FASD for which targeted screening should occur. These include:
	  o Infants/children of mothers registered with the WA Newborn Drug and Alcohol Service, attending alcohol treatment services and those identified as using alcohol and/or other drugs.
	  o Babies that are small for gestational age and/or microcephalic.
	  o Infants/children referred to or in the care of the Department of Child Protection.
	  o Children referred to child development services or Child and Adolescent Mental Health Services, particularly those referred for difficulties with attention, behaviour and social/emotional development.
	  o Children registered with Disability Services Commission with a diagnosis of intellectual disability (ID) or vulnerable to ID, who do not have an established genetic etiology.
	  o Children and adolescents referred to Child and Adolescent Mental Health Services Complex Attention and Hyperactivity Disorders Service.
	• Consideration should also be given to screening:
	  o Children referred to school psychology services for learning and behavioural difficulties.
	  o Youth in juvenile justice settings.
	  o Regional communities identified as having high levels of alcohol consumption.
		screening/diagnostic instrument to assist clinicians, babies and children affected by FASD. This work is part of a national collaboration and is waiting approval from the Department of Health and Ageing before dissemination of the final report /release of the screening instrument.

	• Recommendations around diagnosis outline the need for: o a multi-disciplinary FASD diagnostic service; o clinical pathways for joint FASD assessment with other relevant health services & agencies; o workforce training & development of FASD diagnosis for staff in regional centres; and o scheduled visits & the use of telehealth by metropolitan based FASD assessment team to support regional centres.	
Management Issues		
e.g. access to appropriate care & support services, across sectors.	• Currently no clear or single treatment strategies. Current emphasis prioritises early intervention & effective management of strategies to minimise the effect of primary disabilities & preventing secondary disabilities. • The MOC identifies a need for multi-disciplinary teams & broad management plans to ensure most effective management of FASD individuals. Teams may include clinical staff, caregivers, teachers & access to services including physical, occupational, speech, behavioural & mental health services. • Some children with FASD may already engage with a range of specialised services. It is important these are coordinated and services communicate as many children remain undiagnosed and treatments remain uncoordinated/not specifically targeted to FASD. • Important points to be considered when developing treatment options include: o Matching developmental needs with treatment interventions & adjusting this over time. o Ensuring newborns are monitored & managed for the effects of substance withdrawal. o Providing specific attention & management of sensory issues, sleeping, feeding & nutrition, motor problems, physical anomalies, co-morbid genetic, mental health & other disorders. o Assessing & enhancing the quality of the family/care-giving environment & promoting positive attachment. o Considering the child's wellbeing & safety including the risks	<u>Whole of Government Implementation of the FASD Model of Care</u> The Child and Youth Health Network, WA Department of Health are coordinating a whole of government approach to the implementation of the FASD Model of Care through high level endorsement and the establishment of multisectoral working parties to develop strategies and deliver coordinated services across the continuum of care.

	associated with impairment of parents/carers due to substance use, intoxication or domestic violence. o Providing support for parents/carers through advocacy groups. o Providing multi-systematic interventions including day care, community support, and friendship networks. • The MOC notes the following 'ingredients' to be common across a range of interventions, and integral to their success: o Parent education/training o Explicit instruction of the affected children in order to develop new skills. o Individualised & targeted interventions specific to the deficits among children with FASD can be implemented within a framework of current community services typically available. • Recommendations from the MOC involve: o Mapping referral pathways (including clinical services & family support) to identify gaps & develop additional resources required. o Developing & implementing treatment programs that support the child & strengthen their environmental support systems in order to maximise the child's potential as well as modify secondary effects.	