Fetal Alcohol Spectrum Disorder Framework to guide and support the Western Australian FASD Implementation Plan for the Model of Care

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1. **Introduction**

The Fetal Alcohol Spectrum Disorders (FASD) Framework should be read in conjunction with the FASD Implementation Plan for the FASD Model of Care (MOC). The Implementation Plan (link to be included in final online version) sets out a number of strategies across the continuum of care to address the recommendations of the FASD MOC. In addition, it allocates lead agency responsibility for implementation.

1.1 **Intent**

This Framework is intended to guide and support government and community sector agencies when developing initiatives and programs/services to prevent or address FASD. The Framework sets out:

- the definition of FASD
- guiding principles and criteria to be considered in the development and delivery of FASD prevention/intervention programs
- inclusion criteria
- stakeholder engagement
- background information on the development of the FASD Framework and Implementation Plan.

1.2 **Scope of the WA FASD MOC Framework**

The Framework is managed by WA Health and is applicable to all public health service providers working in health promotion/prevention and with children/adults and their families/carers who are at risk and/or living with FASD.

The Framework is appropriate for adoption by other government departments and community sector agencies implementing strategies to reduce the incidence, risk and manage the burden of FASD.

The focus is on prevention and the broad definitions of primary, secondary and tertiary prevention applicable to this framework are as follows:

- **Primary**: Reducing the number of new cases of the acquired disorder (incidence of FASD).
- **Secondary**: Reducing the prevalence of the disorder by reducing the reoccurrence of a known event (i.e. exposure to alcohol during pregnancy) through early detection and/or prompt intervention.
- **Tertiary** (diagnosis, treatment and management): Reducing impairments and disabilities, minimising symptoms already caused by exposure to risk factors and promoting family adjustment to conditions that cannot be ameliorated.
2. What is FASD?

FASD is the umbrella term used to describe adverse outcomes caused by fetal exposure to alcohol. Features of FASD may include some or all of the following:\(^1\):

- growth retardation
- prenatal growth deficiency (small for gestational age)
- postnatal growth deficiency (lack of catch up growth despite good nutrition)
- low weight to height ratio
- central nervous system anomalies or dysfunction
- developmental delay
- learning and behavioural disorders
- intellectual disability
- microcephaly and/or other structural defects.
3. Principles used to develop strategies

The following principles have been provided to guide the way in which government departments and community agencies develop and apply strategies for the prevention of and/or to reduce the incidence of FASD.

<table>
<thead>
<tr>
<th>Principle</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FASD is preventable</strong></td>
<td>The priority is primary and secondary prevention.</td>
</tr>
<tr>
<td><strong>Across sector responsibility and accountability</strong></td>
<td>Due to the multifaceted nature of FASD, a holistic approach is required, across the continuum of care and inclusive of sectors beyond the health service delivery sectors.</td>
</tr>
<tr>
<td><strong>Coordinated interventions</strong></td>
<td>Stakeholders will collaborate and work in partnership to maximise the best use of resources and opportunities for access to services.</td>
</tr>
<tr>
<td><strong>Accessibility and equitability</strong></td>
<td>Strategies will be responsive to the needs of people from all cultural and linguistic backgrounds, in particular Aboriginal populations, and all socio-economic and educational backgrounds residing in communities across WA, including rural and remote locations.</td>
</tr>
<tr>
<td><strong>Public health principles</strong></td>
<td>Based on the World Health Organization’s Ottawa Charter for public health, health is the result of interactions between people’s personal behaviours, social, economic, political and physical environmental factors.</td>
</tr>
<tr>
<td><strong>Consumer and carer focussed</strong></td>
<td>Strategies will be consumer and carer focussed. Consumers and carers will be consulted and informed about strategies to prevent/manage FASD and the relevance to them, their families and communities.</td>
</tr>
<tr>
<td><strong>Responsive to emerging evidence based policy and practice</strong></td>
<td>Through the governance framework and reporting structure, WA strategies will be included in the national planning and policy development.</td>
</tr>
<tr>
<td><strong>Cultural diversity</strong></td>
<td>When working with Aboriginal people and communities, ensure an approach that respects the rights, values and beliefs of Aboriginal people. Aboriginal leadership, community consultation, direction and involvement form an essential part of this process as does working in partnership with Aboriginal communities.</td>
</tr>
</tbody>
</table>
## 4. Inclusion criteria for strategies

The development of strategies should be based on the following criteria.

<table>
<thead>
<tr>
<th><strong>Based on evidence and best practice models</strong></th>
<th>Where available, the strategies are based on evidence and best practice, adaptable to the current context.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Align with public health principles</strong></td>
<td>The strategies aim to develop personal skills, create supportive environments, strengthen community action, reorientate health services and build responsive public policy.</td>
</tr>
<tr>
<td><strong>Cause no more harm</strong></td>
<td>The strategies aim to minimise harm and consideration has been given to potential unintended consequences.</td>
</tr>
<tr>
<td><strong>Measurable and have been and/or can be evaluated</strong></td>
<td>Measureable outcomes have been aligned with the strategies to begin developing an evidence base for the future.</td>
</tr>
<tr>
<td><strong>Accessible for at risk groups</strong></td>
<td>The strategies aim to provide the best outcomes for the most people, are culturally appropriate and take other access barriers, such as cost, and/or geographical location into consideration.</td>
</tr>
<tr>
<td><strong>Sustainable</strong></td>
<td>The strategies do not rely on the provision of new resources.</td>
</tr>
</tbody>
</table>
5. Stakeholder engagement, participation and consultation

It is important to engage with a broad range of stakeholders from the outset in order to optimise acceptance of the strategy and support for its implementation. The following features are important for effective engagement and consultation processes:

- a balance of representation across sectors and disciplines
- a communications strategy to ensure all stakeholder groups remain informed of progress
- a clear governance and reporting framework to set out roles, responsibility and accountability
- opportunities for targeted and broader stakeholder groups to provide feedback and input into the development of strategies.
6. Background information

The following section includes background information and documents to guide and support the development and implementation of strategies to prevent or reduce the incidence of FASD across the continuum of care.

It includes:

- FASD Model of Care
- FASD Implementation Governance Paper and structure (Appendix 2)
- How were the strategies developed: Continuum of prevention and intervention (Appendix 1)
- List of stakeholder agencies involved in the FASD MOC and Implementation Plan (Appendix 3).
- Useful links and references

6.1 Model of Care

The FASD MOC was developed by the Child and Youth Health Network (CYHN) and a working group of diverse stakeholders. Published in 2010 it describes the current situation of FASD in WA and contains 33 recommendations across the continuum of care, including holistic prevention strategies to reduce the prevalence of this avoidable condition.

6.2 Governance structures for the whole of government commitment

A whole of government approach with the Western Australian Government and health and community service government departments is required to prevent FASD. WA Health’s CYHN works within the governance structure established to support the implementation process for the FASD MOC.

The governance structure serves two roles:

- to outline the governance structure and reporting framework established
- to describe the coordination of multiagency engagement, collaboration, accountability, roles and responsibilities and communications processes.

The organisational structure reflects the need for strong and meaningful partnerships, accountability and reporting and to engage, recruit and coordinate sustainable stakeholder action.

6.3 How were the strategies developed?

Process for developing strategies

The FASD Project Control Group and Implementation Action Groups have used the following process to develop strategies which could provide useful guidance for stakeholder groups developing strategies for implementation across the continuum of care for FASD prevention.

1. Comprehensive mapping and gapping of current activity in WA in consultation with a range of stakeholders.
2. Review of national, state and local evidence base and programs with stakeholders including service providers.
3. Workshops to identify opportunities for further strengthening and engagement of current activities.
4. Identification of leaders and leadership opportunities.
5. Inclusion of enabling factors to develop common understanding of terminology across sectors.
6. Determination of requirements to build capacity of the workforce through development and training initiatives, across the continuum of care.
7. Assessment of risk, taking into account resource requirements.
8. Development of strategies in line with agreed principles and inclusion criteria.

List of stakeholder agencies
Participants involved in the implementation processes include representatives across multiple sectors:

<table>
<thead>
<tr>
<th>Fields of expertise</th>
<th>Sectors engaged</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government agencies (e.g. Community Services Leadership Group (CSLG) and Project Control Group (PCG) representatives)</td>
<td>Health (health promotion, maternity service, child health, child development)</td>
</tr>
<tr>
<td>Statewide policy units</td>
<td>Drug and alcohol</td>
</tr>
<tr>
<td>Non-government organisations</td>
<td>Aboriginal health services</td>
</tr>
<tr>
<td>Researchers</td>
<td>Country health services</td>
</tr>
<tr>
<td>Carers/consumers</td>
<td>Primary health care</td>
</tr>
<tr>
<td>Health Services</td>
<td>Education</td>
</tr>
<tr>
<td>Clinicians</td>
<td>Child protection</td>
</tr>
<tr>
<td></td>
<td>Corrective services</td>
</tr>
<tr>
<td></td>
<td>Disability services</td>
</tr>
<tr>
<td></td>
<td>Mental health</td>
</tr>
<tr>
<td></td>
<td>Sport and recreation</td>
</tr>
<tr>
<td></td>
<td>Culture and the arts</td>
</tr>
<tr>
<td></td>
<td>Community support services</td>
</tr>
</tbody>
</table>
7. Useful links and references

A number of national and state initiatives have informed the Australian Government approach to FASD. It is within this context that WA Health acknowledges and recognises a significant shift in emphasis to the prevention of FASD and the need for an across sector and whole of government response.

These initiatives include:

- Parliamentary inquiries:
  - House of Representatives standing committee on social policy and legal affairs inquiry into FASD report: *FASD: the hidden harm*.
  - WA Legislative Assembly Standing Committee Inquiry into Education and Health Report: *FASD: the invisible disability*.

- Monograph of the Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders. *Fetal Alcohol Spectrum Disorders in Australia: An Update*

- National papers:
  - National Indigenous Drug and Alcohol Committee paper: *Addressing fetal alcohol spectrum disorder in Australia*
  - Foundation Alcohol Research Education (FARE) reports
  - *National Maternity Services Plan*

- Research projects into the prevalence, treatment and management of FASD:
  - *Telethon Institute of Child Health Research into alcohol, pregnancy and FASD*
  - The George Institute for International Health: *Marulu the Lililwan Project*.
### 8. Appendices

**Appendix 1. Continuum of prevention and intervention of FASD**

#### Continuum of prevention and intervention over lifespan

<table>
<thead>
<tr>
<th>Stage of Health Continuum</th>
<th>Well Population</th>
<th>At Risk of fetal exposure to alcohol and Brief Intervention</th>
<th>Diagnosis and Early Intervention of FASD</th>
<th>Management of FASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Prevention &amp; Management</td>
<td>Primary Prevention</td>
<td>Secondary Prevention</td>
<td>Tertiary Prevention and Intervention</td>
<td>Tertiary Prevention and Intervention</td>
</tr>
<tr>
<td></td>
<td>Promotion of healthy behaviours</td>
<td>Early Detection of Risk Factors/Intervention</td>
<td>Disease Diagnosis, Treatment &amp; Management</td>
<td>Disease Diagnosis, Treatment &amp; Management</td>
</tr>
<tr>
<td></td>
<td>Low drinking behaviours</td>
<td>Screening of alcohol use antenatal period</td>
<td>Advice on options for management of FASD</td>
<td>Self Management</td>
</tr>
<tr>
<td></td>
<td>Planned pregnancy</td>
<td>Early intervention/ Brief intervention</td>
<td>Screening and Diagnosis of symptoms</td>
<td>Continuing Care</td>
</tr>
<tr>
<td></td>
<td>Advocacy for low risk drinking environments</td>
<td>Surveillance &amp; recall/ monitoring</td>
<td>Tracking &amp; recall</td>
<td>Monitoring and recall</td>
</tr>
<tr>
<td></td>
<td>Praise of low risk drinking environments</td>
<td>Periodic health examinations</td>
<td>Acute care</td>
<td>Management of complications</td>
</tr>
<tr>
<td></td>
<td>Universal approaches</td>
<td>Coordinated referral pathways</td>
<td>Supportive environments</td>
<td>Education re minimisation of complications</td>
</tr>
<tr>
<td></td>
<td>Social marketing/use of media</td>
<td></td>
<td>Therapy based interventions</td>
<td>Rehabilitation</td>
</tr>
<tr>
<td></td>
<td>Health education</td>
<td></td>
<td>Treatment of symptoms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Regulation and legislation</td>
<td></td>
<td>Management and prevention of secondary complications</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Targeted approaches</td>
<td></td>
<td>Advice on options for management of FASD</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Access to range of strategies to suit cultural &amp; socioeconomic requirements</td>
<td></td>
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</tbody>
</table>

#### Relevant Recommendations from Model of Care

1. Public education & community action, responses to alcohol-related problems
2. Prevent harmful alcohol consumption, responsible supply & service of alcohol.
3. Reduce harmful alcohol consumption by youth, addressing risk factors.
4. Access antenatal & maternity services, disadvantaged groups.
5. Information, all pregnant/families - substance use/risks associated with alcohol use during pregnancy, abstinence.
7. Identify at risk newborns/children for further screening/FASD assessment.
8. Refer suspected FASD to appropriate assessment & intervention services.
9. Include screening in child health nurse screening assessments of children in...
10. Magistrates/juvenile justice officers support potential FASD clients.
11. Clinical pathways, joint FASD assessment + other relevant health services/agencies.
12. Map referral pathways/existing clinical
<table>
<thead>
<tr>
<th>Intervention</th>
<th>Objective</th>
<th>Prevent movement into the “a risk” group</th>
<th>Prevent progression to established disease and hospitalisation</th>
<th>Prevent/delay progression to complications and prevent re-admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Healthy behaviour practices &amp; pre-conception care for females of child bearing years, abstinence from alcohol prior to pregnancy.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>5</td>
<td>Reduce unplanned pregnancy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Opportunistic alcohol consumption screening, all women of child-bearing age + interventions.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Universal screening in pregnancy (first antenatal visit &amp; each trimester) &amp; interventions.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>16</td>
<td>Research - accurately determine prevalence, specific communities/regions &amp; changes in prevalence over time.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Data surveillance and linkage - data linkage ability all sectors - record, evaluate &amp; share health/other needs &amp; service access of FASD individuals.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>18</td>
<td>Workforce training &amp; development in FASD diagnosis, staff in regional centres.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Service delivery and clinical pathways - initiate consultation by DoH - screening into Medicare-funded child health checks &amp; develop clinical pathways/referral protocols.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Coordinated implementation strategies - inter-agency FASD steering group + reference group.</td>
<td></td>
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</tr>
</tbody>
</table>

**Enablers:**

Each stage requires critical assessment of workforce requirement, resource allocation, data requirements, evidence base for intervention (incl. cost effectiveness), quality measures, guidelines and standards, monitoring & evaluation, roles & responsibilities (Commonwealth/State), public/private, equity impact, consumer involvement, etc...

| Research | 33: Research - accurately determine prevalence, specific communities/regions & changes in prevalence over time. |
| | 32: Data linkage ability all sectors - record, evaluate & share health/other needs & service access of FASD individuals. |
| Workforce training & development | 25: Workforce training & development in FASD diagnosis, staff in regional centres. |
| | 30: Training & education to all relevant health professionals - alcohol use in pregnancy, brief intervention, FASD & healthy behaviour change. |
| Service delivery and clinical pathways | 18: Initiate consultation by DoH - screening into Medicare-funded child health checks & develop clinical pathways/referral protocols. |
| Coordinated implementation strategies | 29: Inter-agency FASD steering group + reference group. |
Appendix 2. Governance Structure 2012

**Member Agencies on Project Control Group**
- Department of Health WA
- Drug and Alcohol Office
- Department of Education
- Department of Communities

**Acronyms**
- AHMAC: Australia Health Minister’s Advisory Council (CHAIR: Director General, WA Health)
- APHDPC: Australian Population Health Development Principal Committee (formerly)
- FASD: Fetal Alcohol Spectrum Disorder
- SCoH: Standing Council on Health

**Areas of Responsibility**
- National Committees
- FASD Monograph
- FASD Advice Paper
- Inquiry into FASD

**Areas of Responsibility**
- Leadership and oversight of the WA whole of government responsibility for the implementation of the FASD Model of Care

**Areas of Responsibility**
- WA stakeholders responsible for the development of statewide and local strategies for the development of the FASD implementation Plan – 33 recommendations of the FASD Model of Care as mapped across continuum of prevention

**Overarching National Committees**
- FASD Monograph
- FASD Advice Paper
- Inquiry into FASD

**Leadership and oversight of the WA whole of government responsibility for the implementation of the FASD Model of Care**

**WA stakeholders responsible for the development of statewide and local strategies for the development of the FASD implementation Plan – 33 recommendations of the FASD Model of Care as mapped across continuum of prevention**

**Implementation Reference Group**
(Across sector engagement, with targeted consultation as required)

**Primary Prevention Implementation Action Group**
**Secondary Prevention Implementation Action Group**
**Tertiary Intervention (Diagnosis Treatment & Management) Implementation Action Group**

**Community Services Leadership Group**
(Director General, WA Health representative)
Whole of Government Project Sponsors

**CAHS**
(Chief Executive—corresponding member)
## Community Services Leadership Group (CSLG)

The CSLG is made up of Director Generals from health and human service agencies. Membership includes Government agencies such as:

- Department for Communities (DFC)
- Department for Child Protection (DCP)
- Department of Corrective Services (DCS)
- Department of Culture and the Arts (DCA)
- Disabilities Services Commission (DSC)
- Department of Education (DOE)
- Department of Health (DOH)
- Department of Housing (DOH)
- Department of Indigenous Affairs (DIA)
- Department of Local Government (DLG)
- Lotterywest
- Mental Health Commission (MHC)
- Department of Premier and Cabinet (DPC)
- Department of Sport and Recreation (DSR)
- WA Police Service.

## FASD Project Control Group

The PCG includes representation from:

- WA Health:
  - System Policy and Planning, Aboriginal Health
  - Public Health and Clinical Services
  - Child and Adolescent Community Health
  - Child and Youth Health Network
- Drug and Alcohol Office
- Department of Education
- Department for Communities.
Membership of the three implementation action groups as shown in the 2012 governance structure.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Drug and Alcohol Office</td>
<td>- Telethon Institute for Child Health Research</td>
<td>- Child &amp; Adolescent Community Health Policy</td>
</tr>
<tr>
<td>- Department for Communities</td>
<td>- Lead Child &amp; Youth Health Network</td>
<td>- Child Development Service</td>
</tr>
<tr>
<td>- WA Health -Public Health Division</td>
<td>- State-wide Obstetric Support Unit</td>
<td>- Department for Child Protection</td>
</tr>
<tr>
<td>- School Drug Education Road Aware</td>
<td>- Child &amp; Adolescent Community Health</td>
<td>- Mental Health Commission</td>
</tr>
<tr>
<td>- St John of God Health Care</td>
<td>- Royal Australian College of General Practitioners</td>
<td></td>
</tr>
<tr>
<td>- WA Country Health Service-Goldfields</td>
<td>- Aboriginal Maternity Services Support Unit</td>
<td>- Telethon Institute for Child Health Research</td>
</tr>
<tr>
<td>- WA Health -Aboriginal Health Division</td>
<td>- Curtin University -School of Nursing</td>
<td>- Department of Corrective Services</td>
</tr>
<tr>
<td>- Telethon Institute of Child Health Research</td>
<td>- King Edward Memorial Hospital –Drug and Alcohol Service</td>
<td></td>
</tr>
<tr>
<td>- Department of Education</td>
<td>- Curtin University -Centre for Population Research</td>
<td></td>
</tr>
<tr>
<td>- Child &amp; Adolescent Community Health</td>
<td>- Drug and Alcohol Office</td>
<td>- Department of Education</td>
</tr>
<tr>
<td>- Carer and NOFASARD member</td>
<td>- Department for Child Protection</td>
<td>- Disability Services Commission</td>
</tr>
<tr>
<td>- The Lililwan Research Project.</td>
<td>- North Metropolitan Public Health Unit</td>
<td>- Aboriginal Health Council of WA</td>
</tr>
<tr>
<td></td>
<td>- South Metropolitan Public Health Unit</td>
<td>- Professor, Aboriginal Clinical Child Health</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Paediatricians</td>
</tr>
</tbody>
</table>

NB: Co-leads for each implementation action group are representatives of the bolded agencies.
9. References
