Child and Youth Health Network

Fetal Alcohol Spectrum Disorder Model of Care

Government of Western Australia
Department of Health

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1. Executive Summary

Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder (FASD) is the umbrella term used to describe adverse outcomes caused by maternal exposure to alcohol. The most visible presentation of FASD is Fetal Alcohol Syndrome (FAS). The outcome is affected by a number of factors including the timing, dose and pattern of maternal drinking, as well as other socio-behavioural factors. Therefore, not all pregnancies exposed to alcohol in utero will be affected or affected to the same degree.

Current Situation in Australia

Alcohol is widely used and accepted as part of Australia's society and culture. Research into alcohol consumption shows distinct age-related patterns of drinking and a high prevalence of drinking amongst women who are pregnant. FASD has received much press in recent times and is often incorrectly referred to as an Aboriginal issue; however it is an issue for any individual or group that consumes alcohol at harmful levels. Research has also shown that around 50 % of live births are the result of unplanned pregnancy; therefore many pregnancies may be exposed to alcohol before the woman realises that she is pregnant.

When discussing alcohol use and related harm a variety of terms are used to try and distinguish between drinking at levels that increases the risk of harm and that which is causing harm (be it acute harm that may arise from drinking on a single occasion, or chronic harm which may result from drinking over the longer term). For the purpose of this document, the term harmful has been used as it has been applied in the current National Health and Medical Research Council Drinking Guidelines which recommend that for women who are pregnant or planning a pregnancy, not drinking is the safest option.

Currently, it is believed that the prevalence of FASD in Australia is under-ascertained. This is due to a number of factors including:

- lack of screening
- lack of diagnosis
- lack of sufficient data

Given the lack of reliable prevalence data for Australia it is impossible to estimate the financial and social costs of FASD to our community. However, overseas research suggests the costs to society of this preventable condition are very high when the breadth of effect is considered.

Recommendations

This Model of Care prioritises the use of prevention strategies to reduce the prevalence of FASD, recognising there is no cure for this avoidable condition. Prevention requires a holistic approach. When addressing the issues of alcohol and women's health or pregnancy, health professionals and policy makers should also consider other health, psychosocial, cultural, regulatory and economic factors.

Prevention

It is recommended prevention strategies should be directed at women of child-bearing age, and also 'at risk' groups such as young people and women with an alcohol dependency, as well as the general population to effect a cultural shift. Prevention strategies should be embedded into broader alcohol harm reduction strategies. Key areas of focus include:

- public education programs and support of community action to reduce alcohol-related problems
- school-based education programs
- supporting legislation and enforcement
- routine screening of women of child bearing age and provision of appropriate information to all pregnant women and their families about substance use and the risks associated with alcohol use during pregnancy
- support of pregnant women with an alcohol dependency to manage withdrawal
- provide post-natal support to women with an alcohol dependency to improve parenting and child and family wellbeing
- use of brief interventions by health professionals
- reduction of unplanned pregnancy
- improving the quality, availability and cultural appropriateness of maternity services
- increasing collaboration between health professionals and health services

Screening

Appropriate screening programs will provide opportunities to prevent FASD and provide early intervention for pregnant women with alcohol problems and children diagnosed with FASD.

Universal screening for alcohol consumption is recommended for women of child-bearing age and during pregnancy. Universal screening for FASD is not currently recommended in newborns or children. However at risk newborns and children who should have assessment for FASD should be identified, by history of maternal alcohol consumption, abnormal growth parameters and children referred for developmental delay.

It is also recommended that data collection on alcohol use during pregnancy be routinely collected using alcohol assessment tools.

The Model identifies a number of sub-populations at high risk of FASD for which targeted screening should occur. The Model advocates for collaboration with other related organisations to support children identified with FASD.

FASD educational resources and services need to be appropriate for individual communities, therefore providers need to work with community leaders to ensure what they are providing is culturally appropriate.

Diagnosis

The Model recommends development of a multi-disciplinary FASD diagnostic service for children within the Child Development Service and development of clinical pathways for joint FASD assessment with other relevant health services and agencies.

The Model recognises the need for specific strategies to address service delivery in rural and remote areas and recommends provision of workforce training in FASD diagnosis for regional staff as well as support via scheduled visits and telehealth from the metropolitan-based FASD assessment team.

Therapy Intervention/Care

Existing data suggests that some children diagnosed with FASD already engage with a range of specialised services. This model encourages collaboration of these services as many children remain undiagnosed and treatments are either unco-ordinated or not specifically targeted to children with FASD. The Model recommends mapping of referral pathways, existing clinical services and family support to identify gaps and develop additional resources as required. Treatment programs that support the child and strengthen their environment and support systems should be developed to maximise the child's potential and modify secondary effects.

Advocacy/Partnerships/Coordination

Given the breadth of financial and social implications of FASD an inter-agency approach to prevention, diagnosis and management of FASD is recommended. An inter-agency FASD strategy group should be formed to ensure a co-ordinated, holistic approach.

Workforce and Professional Development/Training and Education

Training and education of all relevant health professionals should be a major priority in recognition of the lack of knowledge and identification of mothers at risk and children affected by FASD. Education needs to be available at multiple levels, including under-graduate, post-graduate and in-service training programs.

Monitoring, Evaluation and Surveillance

There are significant gaps in the current capacity within WA to screen, diagnose and treat FASD. Therefore a number of recommendations are made to assist with identification of gaps and provide evidence to review and modify services to maintain best practice. These include:

- Development of approved channels of agreed and confidential communication between sectors for any child diagnosed with a FASD.
- Facilitation of data linkage ability between sectors to record, evaluate and share the health and other needs of individuals with a FASD to facilitate service access.
- A commitment to undertake further research to more accurately determine the prevalence of FASD in specific communities/regions.

2. Acknowledgements

This model of care is the result of contributions from a large number of organisations and individuals. We would like to sincerely thank them for their time and contribution. We especially thank the efforts of the working party members listed below who were supported by Development Officers, Kerry Stewart and Robyn Richmond, of the Health Networks Branch.

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3. Introduction

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term, referring to the various adverse outcomes that are caused by prenatal exposure to alcohol. FASD therefore encompasses a range of clinically significant effects that have been classified under different diagnoses including fetal alcohol syndrome (FAS), alcohol related neuro-developmental disorders (ARND), alcohol related birth defects (ARBD), fetal alcohol effects (FAE) or partial fetal alcohol syndrome (PFAS).

Children displaying the complete phenotype of characteristic facial anomalies, growth retardation and developmental abnormalities of the central nervous system are defined as having fetal alcohol syndrome (FAS). The unique cluster of facial anomalies that are specific for FAS are short palpebral fissure, smooth philtrum (which may also be long) and thin upper lip (also referred to as decreased lip circularity). These facial characteristics become less distinctive as the child grows.

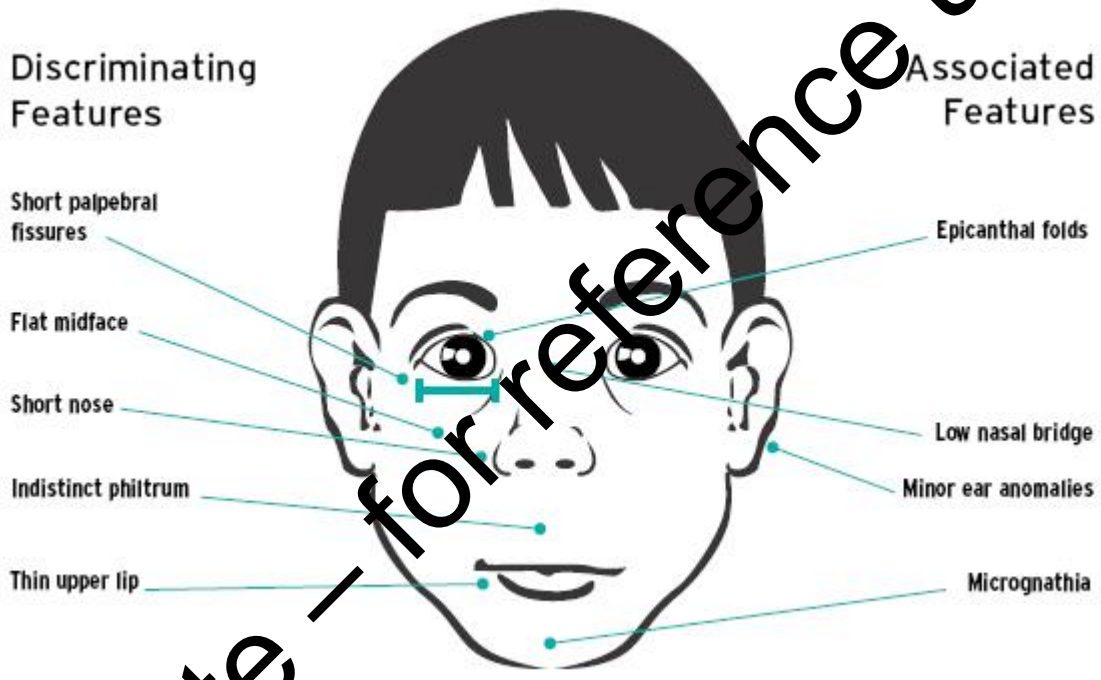

Figure 1: Facial characteristics of FAS[11]

There is a range of other alcohol-related harms not covered under the FASD umbrella such as pre-term delivery, mortality and other alcohol-related problems (see epidemiology, vulnerable groups).

Other features of FASD may include some or all of the following:

- 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

FAS/FASD has been incorrectly considered as an ‘Aboriginal issue’. However it is an issue for any woman from any societal group who consumes alcohol at harmful levels during pregnancy.

4. Epidemiology

Alcohol Use in Australia

> "It's a lot of fate to play with for the sake of a moment's relaxation".[1]

Alcohol consumption during pregnancy needs to be viewed within the wider community attitudes to drinking. Alcohol is widely used in our society and is very much a part of the social and cultural aspects of Australian life.[12] In Western Australia (WA) 86% of people 14 years and older report that they drink alcohol while 10% report that they drink on a daily basis and 47% drink weekly. The majority of Australians consume alcohol at levels that are low risk to their health, however in WA 41% of people report drinking at levels that place them at risk of short-term harm (binge drinking) and almost 11% are at risk of long-term harm.[6]

The pattern of alcohol consumption shows distinct age-related patterns with the highest rates of drinking and drinking at harmful levels occurring in adolescents and young adults. The highest rates occur amongst 20-29 year olds with almost 31% of women in WA drinking at risk of short-term harm at least monthly and 12% at least weekly while the percentages for adolescent females are 23% and 11.5% respectively.[8]

Alcohol Use During Pregnancy

> "If only people could have my brain for a while they wouldn't drink when they are pregnant. It's been hard for me. It would be awful for someone with FAS not to know they have it and not to have parents who wanted to help" [4]

Australian surveys of women have found 14% to 20%[10] report drinking at risk of short-term harm (4+ standard drinks per occasion) during the three months prior to pregnancy. During pregnancy, 50%10,13 to 59%[9] of the women surveyed reported consuming alcohol at some time during pregnancy, with only 41% of women abstaining in all three trimesters.9 Although the majority of women will either abstain from alcohol or will cut down the quantity of alcohol they consume following pregnancy awareness, 36% report drinking alcohol during late pregnancy.10 A significant minority of pregnant women will continue to drink at high levels during pregnancy. Around 11% consume more than two standard drinks and/or more than six drinks per week while around 2.5% binge drink during the second or third trimesters of pregnancy.[9]

Unplanned Pregnancy

Almost 50% of live births in WA in 1995-97 were reported to have been unplanned and when coupled with a high prevalence of alcohol use and misuse in the three months prior to pregnancy[9], many pregnancies will be exposed to alcohol before the women realize that they are pregnant.

Alcohol and Fetal Harm

There are two important factors contributing to fetal harm from prenatal alcohol exposure: the timing and intensity of the alcohol exposure.[14,15]

It is generally accepted that the principal determinant of functional deficit is dose and frequency of alcohol consumption.

The expression of the full Fetal Alcohol Syndrome (FAS) phenotype results from large amounts of alcohol consumed during pregnancy where there is a history of either chronic heavy alcohol use or frequent intermittent heavy alcohol use.[16,17] However, lower levels of alcohol consumption can result in fetal harm. Risk to the fetus has been shown to occur from moderate levels of prenatal alcohol, including occasional binge drinking.[18,19] While the majority of research findings do not support a relationship between low levels of alcohol consumption and fetal harm the evidence base has many weaknesses and limits our ability to draw firm conclusions.[20] A complicating factor in determining the true relationship between the level of alcohol exposure and fetal harm is that the quantity of alcohol consumed in a 'drink' is often larger than a standard drink[21-23] indicating that many women may under-estimate their alcohol consumption.

The dose, pattern, and timing of prenatal alcohol exposure all influence the type of adverse fetal outcomes that occur (Figure 2). Many pregnancy and developmental outcomes, in particular neuro-developmental problems, are sensitive to prenatal alcohol exposure during a specific period of pregnancy.

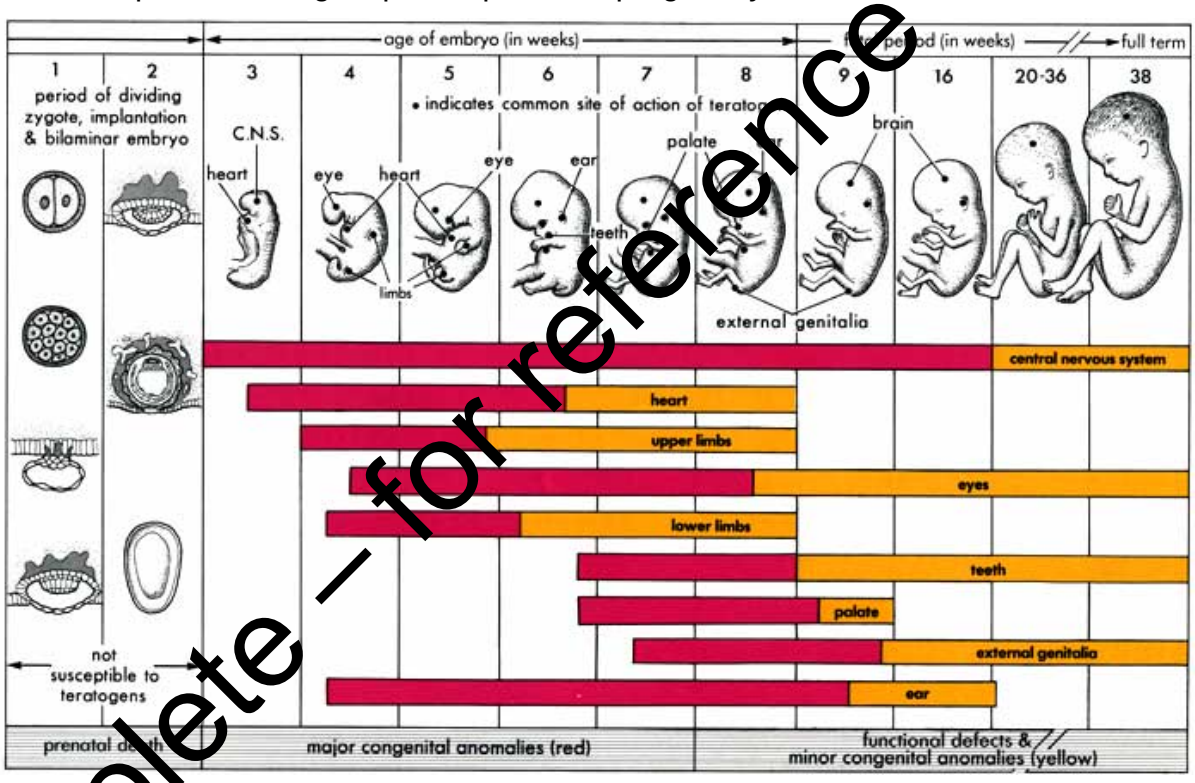

Figure 2: Effect Of Exposure To Alcohol During Specific Periods Of Pregnancy[24]

Prenatal alcohol exposure at moderate (3-4 drinks per occasion)[25] or higher levels increases the risk of child behaviour problems and there is evidence that the timing of exposure influences the type of behaviour problem expressed (Figure 2).[25] For some outcomes such as language delay,[19] the risk to the fetus appears to be highest when there is a binge pattern of alcohol exposure in either the second and/or third trimesters, while anxiety and depression are increased following first trimester exposure to moderate or higher levels of alcohol.[18]

Not all pregnancies exposed to alcohol in utero, even at high levels, will be affected or affected to the same degree. Due to the complex interaction of socio-behavioural

factors (such as poverty, smoking, parity and maternal age), genetic, physiological and fetal factors the effect of alcohol on the fetus can vary.[16]

The National Health and Medical Research Council Drinking Guidelines (2009)[3] recommend that for women who are pregnant or planning a pregnancy, not drinking is the safest option.

Issues Related to Alcohol Use

Women with problems related to their use of alcohol have potentially high-risk pregnancies and yet are less likely to access antenatal care than other women.[26-27] Screening for health problems, regular scans, and preventive services are missed when antenatal care is not accessed and this contributes to the increased risk of poor pregnancy outcomes.[27] Children born to mothers with an alcohol-related dependency are at an increased risk of pre-term delivery,[18, 28, 29, 30] perinatal death,[28, 30] having an Apgar at 5 minutes of <7, being transferred to special care nursery and having a significantly longer length of hospital stay following birth than infants born to women without this dependency.[29] A high rate of cerebral palsy (8%) has also been reported in children of mothers with an alcohol-related dependency[28] which is considerably higher than the incidence of 0.25% reported for the general population.[31]

Although the research evidence is not consistent[32, 33] there is evidence that family conflict, domestic violence,[32, 34-37] and child abuse[34-36, 38-41] are more prevalent in families where one or both parents have problems related to their alcohol use.

Children in such high-risk family environments have an increased risk of experiencing poorer long-term outcomes including lower academic functioning,[34] lower IQ,[42] increased physical and mental health problems,[34] and social and emotional problems.[32, 34, 42]

Birth Prevalence of Fetal Alcohol Spectrum Disorder

It is important to recognise that there is a lack of accurate FAS/FASD research data across all population groups and it is known to be under-ascertained. The prevalence of FAS/FASD varies with the method used for ascertainment of cases and the population examined.

The first report to estimate the prevalence of FAS in Australia was by Bower et al[43] in which the authors linked the Birth Defects Registry and the Rural Paediatric Service database in WA. The prevalence of FAS in WA increased by 38% from that estimated from the Registry alone, giving a rate of 0.02 per 1,000 for non-Indigenous children and 2.76 per 1,000 for Indigenous Australians.

Since this first research paper other Australian studies have found similar estimates of FAS in Australia,[44-46] However, the Australian Paediatric Surveillance Unit recently undertook a prospective study to actively identify cases of FAS across Australia[47] and found considerably lower rates than those reported by the other studies.

The prevalence of FAS in Indigenous children in Australia is similar to the reported high rates for Indigenous people in other countries, but the birth prevalence for non-Indigenous Australians[43, 45] is one-tenth that reported for other countries.[48-49] This is likely to reflect under ascertainment of cases in the non-Indigenous community.[43, 45]

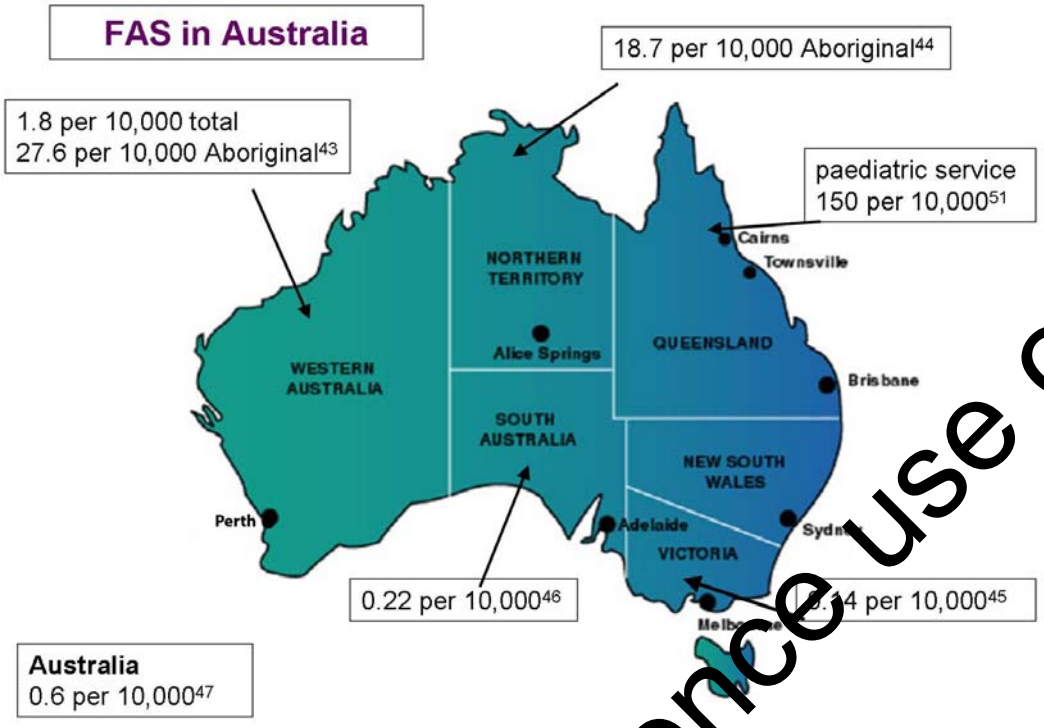

Figure 3: Prevalence of FAS/FASD in Australia[50] WA[43], NT[44],Qld[51], Vic[45], SA[46], Aust[47]

Under-ascertainment of Fetal Alcohol Spectrum Disorder

A number of factors are thought to contribute to under-ascertainment of children with FASD including:

- The absence of routine screening for alcohol use during pregnancy which limits our ability to identify at-risk pregnancies and to investigate the relationship between prenatal alcohol exposure and fetal harm.[52]
- The lack of standardised, routine data collection prevents monitoring and evaluation of maternal alcohol use in pregnancy and research into pregnancy, infant, and child outcomes.[45]
- The lack of routine screening of infants and children known to be at risk of harm from prenatal alcohol exposure, for example in infants whose mothers are known to be dependent on alcohol, contributes to under-diagnosis of FASD.[30, 53]
- Health professionals have limited knowledge of the diagnostic criteria for FASD and many are reluctant to make a diagnosis for fear of stigmatising the family.[52, 54]
- Few health professionals have been assessing children for FASD.[52, 54]

Social and Economic Impacts

It is difficult to obtain a sound picture of the social and economic impact of FASD in Australia. There are no Australian studies of the costs of FASD for individuals or for the community. Given that the prevalence data of FASD in Australia is both under-estimated and incomplete it is not possible to determine the current population costs.

There have been some international studies of the costs of FASD but most of these are limited in scope (both in terms of the numbers of FASD cases and in terms of costs included) and of limited comparability.[55] Nearly all of these studies are limited to FAS and do not include costs for the full spectrum of FASD.

> "Our story is not an isolated case, and our daughter is not alone in her complex, misunderstood disability. On the contrary, she is just one small person among the damaged millions worldwide, all stranded on the colossal iceberg that costs the taxpayers billions and leaves generations of tragic individuals struggling in its wake. The "iceberg" is fetal alcohol spectrum disorder."[5]

The studies generally fall into two categories; the total cost of FAS to the nation, and the lifetime cost of caring for each child born with FAS. US studies have estimated national costs ranging from $US 75 million in 1984 to $US 2.1 billion in 1991[56]. This range is largely influenced by the prevalence rate that was used in the respective study.

Harwood and Napolitano estimated the individual lifetime costs of FAS in the US to be $US596,000 (1980); and the adjusted 2002 cost was estimated at $2 million[56]; $1.6 million of medical care services and $0.4 million for productivity losses.

The social impact of FASD is also difficult to estimate. Once again we rely on what is known about FAS (not FASD) outside of Australia. A study done by Streissguth[57] of 415 patients in the USA with FAS/FAE (6 - 51 years) found that:

- 90% had mental health problems (6 years and over)
- 60% had disrupted education (12 years and over)
- 30% had alcohol and other drug misuse problems (12 years and over)
- 50% had inappropriate sexual behaviour (12 years and over).

Antisocial behaviour, alcohol and substance use and mental health problems are common, with affected individuals often not achieving independent living.[57]

Less is known about the impact of a person with FASD on families. Books written by carers, e.g. The Broken Cord by Michael Dorris or a Alcohol and Pregnancy: A Mother's responsible disturbance by Elizabeth Russell, provide some insight into the daily lives of these families.

Juvenile Justice

The potential adverse life outcomes for individuals with FASD are well known. In the cohort studied by Streissguth et al:[58]

- 60% had got into trouble with the law
- 50% had experienced confinement (detention, jail, prison or a psychiatric or alcohol/drug inpatient setting).

Cohorts of individuals with FAS are well studied to demonstrate significantly high rates of individuals coming into contact with the legal system, but the actual prevalence of FASD amongst the youth in the criminal justice system has not been studied to the same degree.

A Canadian study found a rate of 23.3% having an alcohol related diagnosis in a sample of 287 youth.[59] Another Canadian study addressing the over-representation of Indigenous youth in the criminal justice system, found that Indigenous youths attending a sexual offender treatment programme were more likely to have a background history of FASD, and these youth had higher rates of re-offending.[60]

The juvenile detention rates in WA are quoted as:

- 51.9 per 100,000 juvenile persons
- 654.6 per 100,000 Indigenous juveniles

Both juvenile rates are the highest in the country in this study released in late 2005.61 It is likely that there are significant numbers of incarcerated juveniles in WA with undiagnosed FAS/FASD. Currently the only opportunities for identification are if a magistrate or defence lawyer refer an individual to have their fitness to plea assessed by a psychiatrist or when a juvenile justice officer refers for an assessment.

In many jurisdictions in Canada and the United States, criminal courts are now recognising FASD as being a contributing and/or relevant factor in the criminal justice system. A recent survey of Canadian Judges and Crown Prosecutors to determine their attitudes, knowledge, behaviours and training needs related to FASD indicated that judges and prosecutors saw FASD related disabilities as a pervasive phenomenon in their practice. The judges and prosecutors highlighted their desire and need to receive more support and training in their work with individuals with FASD who come into conflict with the law. They were also seeking ways to take FASD appropriately into account in their practice as well as to identify case law pertinent to FASD.[62]

Individuals with FASD who become involved with the criminal justice system may not understand the arrest and court process; will have diminished competency and capacity; and not fully grasp the severity of the situation.

The findings from the survey of Canadian Judges and Prosecutors suggested that access to accurate and timely assessment and diagnoses of FASD would be beneficial.

5. Prevention

FASD is a tragic, preventable outcome of many cultures' (including Australia's) relationship with alcohol. Alcohol use is widespread throughout the community and there is a high rate of harmful drinking.[6] When risk is widely diffused throughout the community, strategies to reduce overall consumption are needed since per capita consumption of alcohol is an indicator of the number of heavy drinkers in the population.[63] The Australian alcohol drinking guidelines recommend no more than two standard drinks of alcohol per day for men and women and advise pregnant women that the safest choice is to abstain.[3] These guidelines need to be promoted throughout the community. Prevention is about understanding the relationship between alcohol and complex psycho-social issues including aspects of history and culture. A range of prevention efforts will be required including strategies aimed at the whole population, as well as specific groups: school-age children and adolescents, women of child-bearing age, pregnant women, and high-risk women.[64] We have evidence of prevention strategies that reduce per capita consumption and the rate of harmful alcohol consumption[63, 65] and the full-spectrum of interventions need to be implemented in order to achieve the greatest impact.[63] It is also necessary to focus on preventing secondary harms in children affected with a FASD.

- 86% of West Australians drink alcohol, 47% on a weekly basis, and 41% drink at levels that place them at risk of short-term harm[6]
- In WA almost 31% of women 20-29 years of age drink at risk of short-term harm at least monthly and 12% at least weekly[8]
- Around 45% of Australian women drink during pregnancy[9-10]
- Around half of pregnancies are unplanned[9], indicating many will be exposed to alcohol prior to pregnancy awareness

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Prevention of FASD requires a holistic approach. When addressing the issue of alcohol and women's health or pregnancy, health professionals and policy makers should also consider other health, psychosocial, cultural, regulatory and economic factors.

Primary Prevention

Primary prevention strategies to reduce the incidence of FASD need to focus not only on women of childbearing age but also on the general population and be embedded in broader alcohol harm reduction strategies. Primary prevention measures include strategies to change individual behaviour, the community attitudes and systems that support the current drinking culture and environment – all factors that influence how people consume alcohol.

"We must all be agents for 'responsible disturbance' in our community and end the dangers of drinking while pregnant, and identification and support must be provided to the people currently in our society who are affected". [4]

Primary Prevention Recommendations:

Public Awareness and Policy Change

An integrated approach is required to reduce harmful drinking across the population that combines evidence-based social marketing initiatives with policy practices that influence the way alcohol is portrayed and is made available. This approach requires coordinated action nationally, statewide and locally for optimal effect. It is recognised that a reduction in harmful drinking should result in a reduction of overall consumption of alcohol in the community. We would expect that this would have a flow-on reduction of the incidence of FASD.

I am adopted and my mom died so no one will ever know when or how much or how often my mom drank. I just know I have to live with it.[2]

Recommendation 1: Provide public education and community action to support responses to alcohol-related problems

- Co-ordinated community action to address local alcohol problems.
- Social marketing campaigns to discourage tolerance of harmful drinking in the general population.
- Targeted social marketing for females of child-bearing years, including pregnant women and their partners about the risks of consuming alcohol when planning and during pregnancy.
- Provide access to pre-conception information to women of child-bearing age regarding alcohol use.
- Encourage the provision of education in schools addressing alcohol use and pregnancy.
- Culturally appropriate and acceptable strategies for the prevention of FAS/FASD that are informed by local communities.
- Develop strategies in conjunction with relevant Aboriginal organisations and the broader Aboriginal community.

Members of the Fitzroy Crossing community identified harmful alcohol use and related problems as ongoing and requiring intervention. With support the community identified initiatives capable of reducing these problems including alcohol control measures, such as a restriction on the sale of takeaway alcohol. The community has experienced significant health (both acute and chronic), community safety and social benefits.

Recommendation 2: Prevent harmful alcohol consumption through responsible supply and service of alcohol

- Enforcing laws that prohibit access to alcohol and drinking for those under the age of 18 years.
- Responsible alcohol service with enforcement of liquor licensing laws.
- Manage outlet density to prevent and reduce harmful drinking.
- Manage outlet trading hours to prevent and reduce harmful drinking.

The Norseman community undertook a community planning process, in which the Norseman Aboriginal community identified alcohol as the primary factor causing chronic disease and social problems. This has resulted in the development of a successful voluntary Liquor

- Tax alcohol on a volumetric basis and apply effective tax differentials on alcohol to reduce harmful drinking.
- Progressively eliminate alcohol advertising and price discounting.
- Include health warnings on alcohol labels, including warning about drinking during pregnancy.
- Support development and implementation of local alcohol management plans in communities.
- Manage access and supply of alcohol in unlicensed settings.

Recommendation 3: Reduce harmful alcohol consumption by youth by addressing risk factors and promoting protective factors and resilience

- Suitable school organisation and behaviour management to encourage positive interactions and development at school.
- Health promotion in schools, targeting the delayed uptake of alcohol by adolescents.
- Manage access to alcohol by young people in private settings and encourage adult supervision.

Recommendation 4: Promote healthy behaviour practices and pre-conception care for females of child bearing years including promotion of abstinence from alcohol prior to pregnancy

Establish protocols for health professionals to:

- Advise females of child bearing years about the risks of harm from maternal alcohol consumption during pregnancy.
- Routinely screen all women of childbearing age using Audit-C to identify level of harmful drinking.
- Further assess alcohol and related risk factors for women identified as positive using Audit-C.
- Increase the use of brief interventions to address high-risk alcohol use.
- Refer appropriately to drug and alcohol services for assessment and intervention for women identified as having harmful patterns of alcohol use (see Appendix 6 for list of services).

Recommendation 5: Reduce unplanned pregnancy

- Promote the use of brief interventions by health professionals which address both high-risk alcohol use and promote consistent use of contraception in women of childbearing age, particularly women with harmful patterns of drinking and alcohol dependence.
- Develop strategies to promote the use of contraception and to improve the consistency of contraceptive use, including contraception prior to discharge from hospital post-natally.
- Educate and enlist men as partners in family planning.
- Develop strategies to promote communication between partners about the use of contraception.
- Implement evidence-based primary and secondary school drug and sex education.

- Increase the availability of relevant, culturally appropriate courses such as Nuts and Bolts, Core of Life and Mooditj.

Secondary Prevention

Secondary prevention strategies addressing the issue of FASD aim to reduce the risk of alcohol-related harm to the fetus. Strategies will generally be implemented by health professionals and aim to:

- prevent or minimise alcohol consumption by pregnant women
- routinely screen pregnant women for alcohol consumption
- identify and intervene with women who have harmful patterns of alcohol consumption.

Secondary Prevention Recommendations:

Recommendation 6: Improve access to antenatal and maternity services for disadvantaged groups

- Provide culturally appropriate antenatal and maternity services.
- Engage the woman's family to provide support and use a woman-centred and family partnership model of care.
- Provide more antenatal care closer to where people live, including the use of outreach services.

Recommendation 7: Provide information to all pregnant women and their families about substance use and the risks associated with alcohol use during pregnancy including the recommendation for abstinence

Information should preferably be provided in the first trimester and include:

- Alcohol, other drugs and pregnancy – ADF Australian Drug Foundation.
- NHMRC Australian Guidelines to reduce health risks from drinking alcohol (Guideline 4 – Pregnancy and Breastfeeding).
- TICHR Resource List (see Appendix 6).

Information provision and resources will need to take into account the issues of cultural sensitivity, language and literacy.

Recommendation 8: Establish protocols for the use of brief interventions addressing maternal alcohol use during pregnancy

- Refer to Recommendation 4 for more detail.

Recommendation 9: Increase collaboration between GPs, maternity and newborn service providers, alcohol and other drug services to ensure comprehensive drug and alcohol maternity services for all pregnant women, including those in rural and remote regions

- Develop protocols for appropriate referral to alcohol and other drug (AOD) counselling and treatment services for pregnant women identified as having an alcohol-related dependency.
- Develop protocols for referral for pregnant women from AOD counselling and treatment services to appropriate maternity services.

- Develop protocols for a multi-disciplinary inter-sectorial approach which supports these women over their life course.
- Link high-risk women in the antenatal period with community midwives, community health and welfare services to increase the likelihood of maintaining contact following delivery.

Tertiary Prevention

Tertiary prevention strategies target women who have a child with FASD and/or women with an alcohol-related dependency. Tertiary prevention strategies are generally implemented by health professionals and aim to:

- promote the health and wellbeing of the mother during and after pregnancy
- promote the health, wellbeing and development of the child
- address the mother's substance use problems and associated issues
- prevent further alcohol-exposed pregnancies in women identified as having an alcohol-related dependency during pregnancy and women who have a child diagnosed with FASD.

Tertiary Prevention Recommendations:

Recommendation 10: Identify gaps in the provision of antenatal care for women with alcohol-related dependency and develop state-wide protocols to ensure a streamlined process for accessing maternity services.

- Identify barriers to accessing antenatal care and treatment by women with alcohol-related dependency, including personal, cultural and structural barriers.
- Develop strategies and protocols to address identified barriers.
- Develop protocols to address issues of equity and access to specialist services for pregnant women with alcohol-related dependency, particularly for pregnant women living in rural and remote areas.
- Maintain support for women who are unable to stop drinking during pregnancy and focus on gradual reduction in alcohol consumption and harmful patterns of drinking rather than solely on abstinence.

Recommendation 11: Screen for, and manage, alcohol withdrawal for pregnant women

- Implement routine screening of pregnant women who are dependent on alcohol for signs and symptoms of withdrawal.
- Develop state-wide protocols for the management of withdrawal during pregnancy.
- Use CIWA-ar alcohol withdrawal tool on wards and departments in all maternity hospitals, in conjunction with the Next Step Clinical Advisory Service helpline (see Appendix 6).
- It should be recognised that the sudden cessation of alcohol use in women with physical alcohol dependency carries significant risk and therefore expert supervision by a medical practitioner trained in addiction medicine is required.

Recommendation 12: Refer pregnant and post-partum women with alcohol-related dependency to comprehensive health services addressing parenting and child and family wellbeing

- Provision of appropriate follow up and support for women with alcohol-related dependency during their childbearing years including the prevention of subsequent alcohol affected pregnancies.
- Discuss and encourage the use of long term contraception (e.g. Implanon) prior to discharge from hospital.

Key Supports for Implementing Prevention Recommendations:

- Incorporation of relevant prevention recommendations by key stakeholders into:
  - policies, procedures, and guidelines
  - practice guidelines
  - professional development; capacity and competency.
- Education and training programs for health professionals, and in-service training programs for staff (see section 10).
- Education of key stakeholders about the issue of FASD and prevention strategies relevant to their profession.
- Provision of alcohol and pregnancy resources for health professionals, women, and the general community.
- Monitoring and evaluation of implementation of policy, programs, outcomes and the effectiveness of strategies (see section 11).

6. Screening/Early Detection

Criteria for a screening test are listed in Appendix 2.

Rationale for Screening for FASD

Fetal alcohol syndrome is the most common preventable, non-genetic cause of intellectual disability.[66] The broader spectrum of disability associated with exposure of the fetus to alcohol in pregnancy (FASD) involves considerable morbidity and costs to society. The effects of FAS/FASD occur in early childhood and persist throughout life.

Adverse outcomes are more likely to occur in adolescence and adulthood without intervention earlier in the course of the condition. Therefore, there is a window of opportunity in screening for FASD in early and middle childhood, in order to provide intervention and to prevent or minimise adverse outcomes. Identification of one child affected by FASD in the family also allows the opportunity for prevention of second and subsequent children being exposed to alcohol in pregnancy through maternal and family interventions. However, there is no existing standardised screening test for FASD in Australia. Screening tests do exist for detecting developmental delay in childhood and for detecting behavioural and social/emotional difficulties in children, which may be markers for FASD but do not alert for the possibility of FASD.

Adverse outcomes associated with FAS/FASD include:

- poor educational outcomes
- mental health disorders
- social and relationship difficulties
- poor economic circumstances in adulthood
- law-breaking behaviour
- alcohol and drug use problems

Timing

In consideration of universal screening, there are discrete time points at which screening activity could occur in:

- women during pregnancy
- newborns
- early childhood or at enrolment in full-time education (age 4-6 years).

Targeted Screening

Targeted screening involves identifying sub-populations at high risk of the disorder. The following list describes sub-populations potentially at high risk of FASD:

- 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.
- Babies that are small for gestational age and/or microcephalic.
- Infants/children referred to or in the care of the Department of Child Protection.

"It is easy to be the occasional, ministering angel. But it is not easy to live day in and day out with a child disabled by Fetal Alcohol Syndrome or Fetal Alcohol Effect".[1]

- 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.
- 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.
- Children and adolescents referred to Child and Adolescent Mental Health Services Complex Attention and Hyperactivity Disorders Service.

Consideration should also be given to screening:

- Children referred to school psychology services for learning and behavioural difficulties.
- Youth in juvenile justice settings.
- Regional communities identified as having high levels of alcohol consumption.

Appendix 2 details the analysis for the following screening methods:

- Antenatal screening for alcohol consumption.
- Screening of newborns for fatty acid ethyl esters in meconium.
- Screening of newborns by growth parameters.
- Measurement of growth parameters of infants and pre-schoolers by health professionals.
- Developmental screening in infancy.
- Screening by child health nurses using (PEDS) and Ages and Stages Questionnaires (ASQ, ASQ-SE).
- Screening by digital facial photography or manual tools such as Palpable Fissure Length (PFL) ruler and philtrum guides and growth measurements.

Based on the analysis in Appendix 2, the following recommendations are made:

Recommendation 13: Implement opportunistic screening for alcohol consumption for all women of child-bearing age and the use of brief interventions where indicated

Recommendation 14: Implement universal screening in pregnancy (first antenatal visit and each trimester) and the use of brief interventions where indicated

- Use of a standardised self-report questionnaire (Audit-C) administered by health professionals (see Appendix 4).
- Use of brief interventions where indicated (see section 5, recommendation 4).
- Screening and intervention tools will need to take into account cultural sensitivity, language and literacy.

Recommendation 15: Implement the routine collection of data on alcohol use during pregnancy for the Maternity and Child Health Information Division with annual reporting in the WA Perinatal Statistics Report

- Quantifying maternal alcohol use in each trimester will aid in the implementation of health promotion and prevention strategies, identification of high-risk pregnancies, and early intervention for both affected infants and women requiring referral for further management.

Recommendation 16: Identify at risk newborns and children for further screening and possible FASD assessment

Prospective active case ascertainment would occur through multi-stage population screening. The first step is the identification of children at risk including:

- Newborns and children of women with alcohol-related dependency or women who report alcohol use in pregnancy. .
- Newborns with abnormal growth parameters, including small for gestational age and/or microcephaly.

In the second stage infants with identified risk factors, would be invited to attend the child health clinic for developmental screening at a specified age, e.g. 18 months. Children with developmental concerns would then be referred for further assessment.

Targeted screening would occur for selected sub-populations including:

- Children referred to the CDS and other child developmental services for developmental delay. (In this context the initial screening method would be – the mothers of all children who attend CDS participate in clinical interview and are asked about their alcohol consumption in pregnancy. Those who screen positive are referred for further screening).
- Siblings of identified cases of FASD.
- Other at risk groups (see below):
  - children under the care of DCP
  - children of mothers attending alcohol treatment services
  - youth in juvenile justice settings
  - children from regional areas and communities identified as having high levels of alcohol consumption.

The screening method will vary according to the characteristics of the target population and the health care setting.

Further screening and identification of other risk factors will usually be required before proceeding to full FASD assessment.

Recommendation 17: Refer children with suspected FASD to appropriate assessment and intervention services

- Include identified FASD risk factors in referrals from child health nurses and others to the CDS or other appropriate service.

Recommendation 18: Initiate consultation by Department of Health with Department of Health and Ageing, Divisions of General Practice and the Aboriginal Health Council of WA to consider the incorporation of screening for FASD into Medicare-funded child health checks and to develop clinical pathways and referral protocols

Based on the analysis of different screening methods it is recommended that the following screening is not implemented:

- universal screening by digital facial photography
- universal newborn screening by meconium analysis.

Children in the Care of the Department for Child Protection

Children in the care of the Department for Child Protection are a recognised high risk group for FASD.

A collaborative trial has commenced between Department for Health and DCP to improve health surveillance and health care for children in the care of DCP in two metropolitan and two rural areas. As part of the project every child who is newly placed into care and is between the ages of birth and school entry will receive a Child Health Nurse screening assessment, medical assessment by general practitioner and dental examination. The children will also be required to have an annual health care plan. School aged children will be assessed by School Health Nurses for social and emotional difficulties using the Strengths and Difficulties Questionnaire.

Recommendation 19: Include screening for FASD in child health nurse screening assessments of children in the care of the Department for Child Protection

- Use a combination of assessment of growth parameters, child developmental screening and ante-natal exposure to alcohol.

Children of Mothers Attending Alcohol Treatment Services

Recommendation 20: Develop clinical pathways for screening and/or assessment of children of mothers attending drug and alcohol treatment services

- Ensure collaboration between drug and alcohol treatment services and CACH and WACHS.
- Refer children under 6 years old to a local community child health nurse for developmental screening and referral as necessary.

Youth in Juvenile Justice Settings

Recommendation 21: Work with magistrates and juvenile justice officers to support potential FASD clients

- Develop appropriate FASD identification processes within juvenile justice.
- Develop FASD referral pathways for appropriate cases for multi-disciplinary assessment.

Regional Areas and Communities Identified as Having High Levels of Alcohol Consumption

Several communities across Western Australia have self-identified as having high levels of alcohol consumption. Community members have raised concerns about the high prevalence of FASD across generations and its impact on individuals and the community. These communities have developed their own resources and strategies to address alcohol consumption and prevention of FASD (see above).

Recommendation 22: Ensure FASD education resources and services are appropriate for individual communities

- Work with community leaders to raise awareness and develop education resources for FASD appropriate to their local community.

- Work with community leaders to develop screening and diagnostic services for FASD appropriate to their local community.

7. Diagnosis

Children with FASD may present with a range of symptoms and impairments in development, learning and behaviour. Some of the symptoms related to neuropsychological impairment may be present in early childhood, while other symptoms may be recognised only after the commencement of formal education.

> You cannot see my disability on the outside, I like to make myself look pretty and like to wear cool clothes like the other kids. People seem to notice me and I stand out in a crowd. I laugh loudly, walk loudly and talk loudly. I like a good time.[2]

These symptoms may be attributed to other disorders such as intellectual disability, learning difficulties, Attention Deficit Hyperactivity Disorder or Conduct Disorder.

There is no single internationally accepted classification system for FASD. However, the two dominant classification systems, both originating in North America, are the Hoyme revised Institute of Medicine criteria and the University of Washington 4-digit diagnostic code. Given the University of Washington system is well evaluated, multi-disciplinary and some WA Health staff are already trained in this method, it is recommended that this diagnosis system be adopted across WA.

Common to the different classification systems for FASD is the need to assess characteristics of growth, facial features, neurological structure and function and alcohol exposure in pregnancy. Medical and nursing professionals can provide screening and initial assessment of most of these characteristics. There is international agreement that diagnosis requires assessment, using standardised assessment tools, by a multi-disciplinary team of nursing, medical and allied health professionals.

Metropolitan Diagnostic Service

A multi-disciplinary team should be developed that includes FASD accredited paediatricians and allied health professionals including social work, psychology, speech pathology and occupational therapy. This team would offer a diagnostic service to children eligible for the Child Development Service (CDS) with research support from tertiary institutions. Processes for joint assessment of children and adolescents and collaborative case management, will be developed between the CDS and other relevant health services, including the Child and Adolescent Mental Health Service and the Neurosciences Unit, and external agencies, such as the Department of Education and Training. FASD is a lifelong condition and there are undiagnosed affected adults in our community. However, at this stage there is no plan for a formal adult diagnostic service. This doesn't preclude the diagnosis of FASD in adults by health professionals.

Recommendation 23: Develop a multi-disciplinary FASD diagnostic service for children within the Child Development Service

Recommendation 24: Develop clinical pathways for joint FASD assessment with other relevant health services and agencies

Eligibility for the Child Development Service

The eligibility criteria for the Child Development Service include:

- The child is aged between 0 and 16 years.
- The child either has symptoms of developmental delay or is at risk of developmental delay/disorder in one or more of the following areas:
  - speech/language development
  - social/emotional development
  - motor skills, including fine and gross motor skills
  - attention skills, learning and behaviour.

Indicators for FASD Diagnostic Team Assessment (within the Child Development Service)

- The child meets eligibility criteria for the Child Development Service AND any of the following (adapted from Center for Disease Control FAS referral guidelines)7:
  - There is any report of concern by a parent or caregiver (foster or adoptive parent or DCP caseworker) that the child has or might have FAS/FASD.
  - There is known prenatal alcohol exposure in the high-risk range (i.e. 7 or more drinks per week or 4 or more drinks in one sitting on multiple occasions, or both).
  - One or more facial features are present in addition to growth deficits in height or weight, or both.
  - All three facial features are present.
  - Positive screening result (see section 6).

Clinical Pathways

Given the current low rate of identification of FASD it is important to raise awareness in health and other government departments and agencies and if appropriate to develop joint protocols for referral for FASD diagnostic services.

Figure 5 illustrates the process from referral to diagnostic assessment within the Child Development Service (CDS). The FASD Diagnostic Team Coordinator will process referrals and obtain and collate all relevant information prior to clinical assessment. This information includes:

- birth records
- growth records
- history of out-of-home care if relevant
- school reports
- medical and allied health assessment reports.

By collecting this prior information the multi-disciplinary team can more effectively plan the assessment process and avoid duplication. The FASD Diagnostic Team Coordinator also provides a point of contact for families and referees. The clinical pathway includes a decision point related to the age of the child.

If a child is already attending formal education and no previous neuro-psychological assessment has been performed, initial psychometric assessment by a Department of Education and Training educational psychologist should be considered.

For children of any age, the service would offer initial contact by the team social worker and/or other CDS clinician. The continuing role of the social worker (or other clinician) includes:

- assessment of the family's goals in seeking diagnosis
- assessment of the family's preparedness to accept a diagnosis
- current family circumstances
- parental perceptions of the child's strengths and difficulties
- assessment of stresses and challenges for the family
- existing support networks and community services.

If the family includes the birth mother, the social worker may also assess the mother's attitudes and behaviours in relation to alcohol consumption in pregnancy, current drug and alcohol use and need for professional support for alcohol rehabilitation. It is recognised that the diagnosis of FAS/FASD is likely to provoke reactions of guilt and grief in the parent and the social worker's role also involves establishing a relationship of trust and respect and supporting the parent through the assessment process. If families are from Indigenous or CALD backgrounds, the team would also engage a culturally appropriate health worker to support the family in engaging with the diagnostic service and to assist the health professionals in ensuring cultural security throughout the assessment process.

The next step in the diagnostic process is assessment by the team paediatrician to identify whether there are sufficient clinical indicators for full FASD diagnostic team assessment.

For children older than 6 years, neuropsychology assessment is essential in order to examine the functional neurological deficits associated with FAS/FASD. Therefore, children older than 6 years would be referred to the Neurosciences Unit, Graylands Hospital. The clinical pathway proposes that the Child Development Service and Neurosciences Unit adopt a process of collaborative case management for children with FASD. Similar models of joint assessment and collaborative case management could be developed with other service providers such as Child and Adolescent Mental Health Services (CAMHS).

Rural and Remote Service Delivery

It is recognised that some some rural and remote communities have a high prevalence of FASD and have limited health and developmental services due to their remoteness. This offers a significant challenge to the provision of diagnostic and therapeutic services. Models of service delivery to rural and remote areas could include:

- Workforce training and development in regional centres to provide a local service. This should be prioritised according to level of need, ie according to established or estimated prevalence of FASD in local communities.
- Scheduled rural visits by a metropolitan-based team with the opportunity of assessing whole subpopulations within a short time period and providing education and support to local services. Involvement of the local health service

providers in the visiting team's assessment process will enable building of local expertise.

- Telehealth models for individual assessment.

Recommendation 25: Provide workforce training and development in FASD diagnosis for staff in regional centres

Recommendation 26: Provide scheduled visits and use of telehealth by metropolitan based FASD assessment team to support regional centres

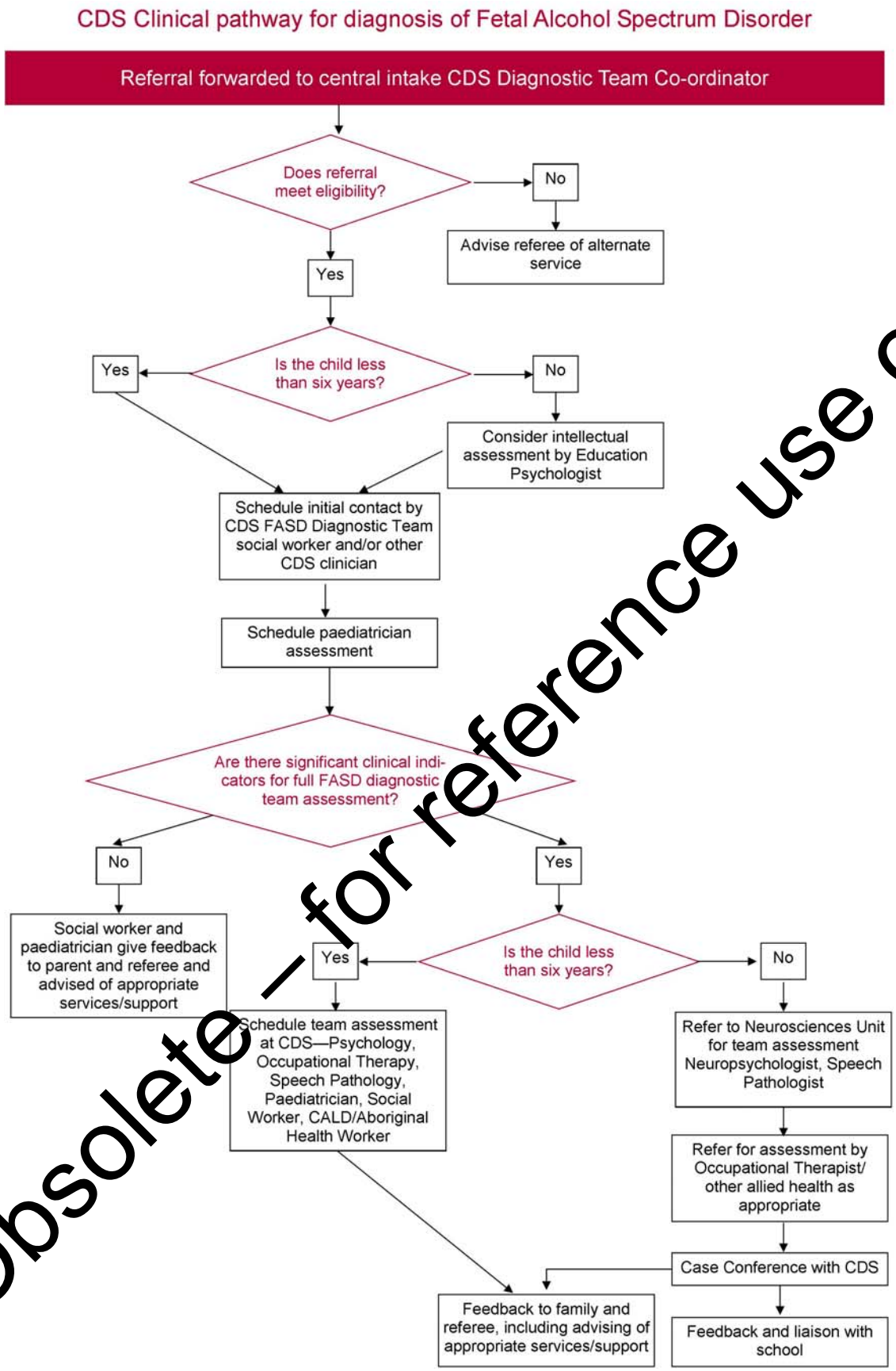

Figure 4: CDS clinical pathway for diagnosis of FASD

Therapy/Intervention/Care

The principles of management have been described in a recent systematic review of FASD.[7] Although there were no clear conclusions that could be drawn with regard to specific interventions, current guidelines discussed the importance of early intervention and effective management strategies to minimise the effect of primary disabilities and prevent secondary disabilities.

> "..Individuals with FASD benefit from a broad management plan, which requires the support of clinical staff, caregivers and teachers. Individuals need access to multiple services (e.g. physical, occupational, speech, behavioural, mental health). Older children need practical interventions such as improving skills of daily living, specific job skills and money management. There was insufficient evidence in the literature to recommend any specific management strategies."[7]

This review concluded that there was broad agreement in the literature of the need for multi-disciplinary teams in order to ensure optimal management of individuals with FASD. The review also recognised that the specific disabilities experienced by individuals with FASD can vary significantly and consequently each individual requires a personalised management program. It is recommended that assessment is undertaken as early as possible in life and repeated at pivotal developmental stages and transition periods.

Other studies have highlighted the need for extended support for families to provide a stable home environment and parenting strategies to promote child and family functioning and manage problem behaviours. In addition they have recommended working with the mothers to prevent further affected pregnancies as an integral part of treatment beyond the standardised prevention mechanisms.

> It's not something you can do on the side – it's a full life commitment. They don't accompany us on our life's journey, they sweep us off the path and down their own rocky roads with a flash flood. We grasp at sandbars along the way; find temporary high ground only to be swept away again by the tidal wave of FASD. Our consolation is that, together, this child might survive those rapids. Alone, they drown along with the sorrows of their birth mothers in the alcohol that has condemned them. Can we teach them to swim? Maybe. Can we keep them alive? Maybe. Can we let go and watch them drown alone? Impossible. Claudia Barker, Bastrop, Texas.[5]

There are often complex social and associated environmental factors which have a number of implications for treatment of children with FASD[67]. Co-morbid conditions of domestic violence, alcohol and other substance dependence in the mother and extended family, financial implications related to parental alcohol abuse and/or disability and/or parenting a child with disability are all important issues to consider in developing treatment options. Important points raised included:

- Matching developmental needs with treatment interventions and adjusting this over time.

- Ensuring that newborns are monitored and managed for the effects of substance withdrawal.
- Providing specific attention and management of sensory issues, sleeping, feeding and nutrition, motor problems, physical abnormalities, co-morbid genetic, mental health and other disorders.
- Assessing and enhancing the quality of the family/care-giving environment and promoting positive attachment.
- Considering the child's wellbeing and safety including the risks associated with impairment of parents/carers due to substance use, intoxication or domestic violence.
- Providing support for parents/carers through advocacy groups.
- Providing multi-systemic interventions including day care, community support, friendship networks.

A recent review of interventions for children with FASD looked at five innovative research projects. Although the interventions were diverse a number of consistent basic ingredients were common to their success:

- Parent education or training that is built into the general framework guiding all the studies.
- Explicit instruction of the affected children in order to develop new skills.
- Individualised and targeted interventions specific to the deficits among children with FASD can be implemented within a framework of current community services typically available.68

Data from a 2001 Australian Paediatric Surveillance Unit report[69] suggests that Australian children with FASD already use a range of specialist paediatric, child development, disability, community, remedial education, respite and psychological medicine services, however many children have not yet been diagnosed and treatments are not specific to children with FASD and are not co-ordinated.

Recommendation 27: Map referral pathways, existing clinical services and family support to identify gaps and develop additional resources as required

Recommendation 28: Develop and implement treatment programs that support the child and strengthen their environment and support systems in order to maximise the child's potential as well as modify secondary effects

- Provide therapeutic services and treatment options that are:
  - individualised, evidence-informed, multi-modal (addressing attitudes, behaviours, cognition and environment)
  - multi-systemic (including multi-agency care, consultation and advocacy) in all relevant environmental settings
  - culturally appropriate and developed in collaboration with families and communities
  - local, accessible and based on a care co-ordination model.
- Ensure access to appropriate early childhood education and developmental services, as well as behavioural and mental health services.

- Provide a supportive environment for people with FASD and their families through promoting greater awareness of FASD among the general community, and among relevant service providers.

8. Advocacy/Partnerships/Coordination

In recognising the need for an inter-agency approach to the prevention, diagnosis and management of FASD, the Department of Health endorses collaboration and partnerships with other agencies, organisations and stakeholders. Primary, secondary and tertiary prevention efforts provide first line defence against the effects of alcohol in pregnancy and secondary disorders can be managed more effectively with early intervention. The health, education and justice systems, communities, employers and individuals all play a role in the effective prevention, detection, intervention and management of FASD.

The aim is to build on expertise, create linkages and strong partnerships and provide opportunities for sharing information and evidence based practice in all sectors. The focus should be on prevention, early intervention, meeting current needs of people with FASD, and strengthening and expanding systems of support, services and resources.

The principles underpinning successful collaboration and partnerships include:

- leadership
- mutual respect for respective agency roles and expertise
- commitment and active participation
- information management and exchange.

Recommendation 29: Form an inter-agency FASD strategy group supported by a reference group

The strategy group would be a small strategically-focussed group. Its membership would comprise senior managers from Government agencies primarily responsible for responding to FASD. These agencies should include the Departments of Education, Health, Communities, Indigenous Affairs and Child Protection; Disability Services Commission; and the Drug and Alcohol Office. The terms of reference for this group would include to:

- Develop and coordinate an across Government statewide plan for FASD.
- Monitor and support the implementation of the FASD Model of Care recommendations.
- Develop a communications plan to inform all identified stakeholders of the policies, guidelines and activities of each agency in relation to FAS/FASD management.
- Review and provide recommendations on policy development related to FAS/FASD.
- Agree on inter-agency referral pathways and protocols for FASD.
- Facilitate the exchange of information between identified stakeholders on activities and advice of their policies, guidelines and activities in relation to FAS/FASD management.
- Respond to prevalence data and clinical reports indicating high or increasing rates of FASD at a community/regional level with whole of government mechanisms that can instigate timely interventions (eg supply reduction and community education)
- Consider eligibility for funded school support for children diagnosed with FASD.

- Develop generic education resources for service providers and people working with FASD and their families. These resources need to be culturally relevant.

A reference group should be formed to seek comment and provide feedback about issues on an as-needs basis. The suggested list of reference group members is listed in Appendix 2.

Many children suspected of having FASD may be identified by other agencies. These children may require diagnostic assessment and referral to WA Health. Recommendations to other agencies regarding potential referrals to WA Health include:

- Children under the age of 12 years with a query diagnosis of FASD are best referred to child development services or visiting paediatric services (for rural and remote patients) for formal assessment.
- Adolescents with a possible diagnosis of FASD would be best assessed by the Child and Adolescent Mental Health Service and their Complex Attention and Hyperactivity Disorders Service.
- Adult clients would be best served through the Neuro-Psychiatric Service of the Adult Mental Health Service.

9. Workforce and Professional Development/Training and Education

There is a recognised lack of knowledge of FASD by health professionals, poor identification of mothers at risk and children affected and limited capacity and competency of the health workforce to deliver identified prevention strategies and therapy. Therefore, training and education of all relevant health professionals, trainees and students should be a major priority. Education needs to be available at multiple levels, including under-graduate, post-graduate and in-service training programs.

Recommendation 30: Ensure all relevant health professionals receive training and education on alcohol use, FASD and supporting healthy behaviour change.

Health professionals for whom this training would be most relevant include:

- antenatal and maternity care providers including midwives, general practitioners, obstetricians and others
- child health nurses and school health nurses
- child development service providers including allied health professionals
- paediatricians and neonatologists
- Aboriginal health workers
- health promotion officers
- drug and alcohol service providers.

Education and training programs should include:

- alcohol use patterns
- harmful alcohol consumption and its identification and prevention
- alcohol and pregnancy
- impact of FASD on individuals and families
- screening for alcohol use in women of child-bearing age and during pregnancy
- brief interventions for alcohol consumption
- appropriate referral processes for both women and infants/children at risk
- FASD prevention, screening, diagnosis and therapy/intervention care

Support for staff providing services for families affected by FASD:

- Provide a dedicated support structure for generalist health staff by specialists with expertise in FASD.

10. Monitoring, Evaluation and Surveillance

Information Systems and Data Collection

Research within WA and Australia demonstrates significant gaps in the capacity to prevent, screen, diagnose and treat the clinical manifestations encompassed by FASD. Continued prospective and systematic recording of information within services established to provide prevention, screening, diagnosis and therapeutic services for FASD will identify closure of clinical gaps, highlight where gaps in care persist, and provide evidence to review and modify services to maintain best practice.

There is already a capacity for confidential data within and across government sectors to be ethically linked and analysed, but ideally, children with FASD would benefit from an agreed and dedicated system allowing inter-sectorial data linkage which will provide evidence for best practice in all aspects of care and prevention. Ongoing research into FASD within health, together with partner agencies and across government sectors, will ensure the model of care within each sector is well informed to meet the diverse requirements of what is really a novel patient group.

The lifelong care of children with FASD may see the principal care shift from one sector to another, but each sector provides important information and insight into the strengths and difficulties specific for each individual. Developing approved channels of agreed and confidential communication between health, education, child protection and justice sectors for any child diagnosed within the spectrum of FASD would assist in optimal care for these individuals across their lifespan. Embedded within the process of sharing confidential information would be a remit to allow specific indices to be collated within a data linkage dedicated to auditing the physical and psychological health, educational and social needs of an individual with FASD.

Recommendation 31: Develop approved channels of agreed and confidential communication between sectors for any child diagnosed with FASD

Recommendation 32: Develop data linkage ability between sectors to record, evaluate and share the health and other needs and service access of individuals with FASD

In order to maintain a best practise model of care for FASD there needs to be:

- Systematic prospective data collection of information about alcohol use for every pregnancy.

  Systematic retrospective data collection of information about alcohol use in pregnancy for every child identified with a developmental disability.
- Systematic recording of FASD as a distinct diagnostic category.
- Systematic reporting of FASD to the birth defects registry.

At Risk Communities

Although Aboriginal communities have been previously identified as having a higher prevalence of FASD, international researchers have cautioned that before it can be concluded that Aboriginal children are at an increased risk of being born with FAS/ARBEs, important questions should be addressed. Research examining how demographic, socio-economic and socio-cultural factors may be related to an increased risk of FAS/ARBEs for some Aboriginal groups needs to be conducted.[70] Furthermore, obtaining an accurate measurement of the prevalence of FAS/ARBEs in a given region involves the study of every family and child or, at least, selecting a representative sample from the region on which to carry out screening.

Recommendation 33: Undertake further research to more accurately determine the prevalence of FASD in specific communities/regions and monitor changes in prevalence over time.

11. References

1. Dorris M. The Broken Cord, A Father's Story: Warner Books; 1992.
2. Kulp L. The Best I Can Be: Living with Fetal Alcohol Syndrome/Effects; 2000.
3. National Health and Medical Research Council. Australian Guidelines to reduce health risks from drinking alcohol. Commonwealth of Australia; 2009; p. 67-82.
4. Russell E. Alcohol and Pregnancy A Mother's responsible disturbance. Burleigh: Zeus Publications; 2005.
5. Buxton B. Damaged Angels. New York: Carroll and Graf Publiishers; 2005.
6. Kalic R, Gunnell A, Griffiths P, McGregor C. National Drug Strategy Household Survey 2007: Summary Tables, Western Australian Households; Drug and Alcohol Office Surveillance Report: No. 1. Perth, Western Australia: Drug and Alcohol Office; 2009.
7. Elliott L, Coleman K, Suebwongpat A, Norris S. Fetal Alcohol Spectrum Disorders (FASD): systematic reviews of prevention, diagnosis and management. HSAC Report 2008;1(9).
8. Australian Institute of Health and Welfare. 2004 National drug strategy household survey, first results. Canberra: Australian Institute of Health and Welfare; 2005. Cat. no. PHE 57.
9. Colvin L, Payne J, Parsons D, Kurinczuk JJ, Bower C. Alcohol consumption during pregnancy in nonindigenous West Australian women. Alcoholism: Clinical and Experimental Research 2007;31(2):276-84.
10. O'Callaghan FV, O'Callaghan M, Najman JM, Williams GM, Bor W. Maternal alcohol consumption during pregnancy and physical outcomes up to 5 years of age: a longitudinal study. Early Hum Dev 2003;71(2):137-48.
11. http://www.beststart.org/resources/alc_reduction/pdf/participant_hndbk_june05.pdf. Supporting change: Preventing and Addressing Alcohol Use in Pregnancy. In. Ontario: Best Start: Ontario's Maternal, Newborn and Early Child Development Resource Centre,; 2005.
12. National Expert Advisory Committee on Alcohol. Alcohol in Australia: issues and strategies. Canberra: Commonwealth Department of Health and Aged Care; 2001.
13. Australian Institute of Health and Welfare. Statistics on drug use in Australia 2004. Canberra: Australian Institute of Health and Welfare; 2005.
14. Matthews SG. Early programming of the hypothalamo-pituitary-adrenal axis. Trends Endocrinol Metab 2002;13(9):373-80.
15. Clarren SK, Astley SJ, Gunderson VM, Spellman D. Cognitive and behavioral deficits in nonhuman primates associated with very early embryonic binge exposures to ethanol. Journal of Pediatrics 1992;121(5 Pt 1):789-96.
16. Jacobson JL, Jacobson SW. Drinking moderately and pregnancy. Effects on child development. Alcohol Res Health 1999;23(1):25-30.
17. Rosett HL. A clinical perspective of the Fetal Alcohol Syndrome. Alcoholism: Clinical Experimental Research 1980;4(2):119-22.

18. O'Leary CM, Nassar N, Kurinczuk JJ, Bower C. The effect of maternal alcohol consumption on fetal growth and preterm birth. British Journal of Obstetrics and Gynaecology 2009;116(3):390-400.
19. O'Leary C, Zubrick SR, Taylor CL, Dixon G, Bower C. Prenatal alcohol exposure and language delay in 2-year-old children: the importance of dose and timing on risk. Pediatrics 2009;123(2):547-54.
20. Henderson J, Gray R, Brocklehurst P. Systematic review of effects of low-moderate prenatal alcohol exposure on pregnancy outcome. British Journal of Obstetrics and Gynaecology 2007;114(3):243-52.
21. Kaskutas LA, Graves K. Pre-pregnancy drinking: how drink size affects risk assessment. Addiction 2001;96(8):199-209.
22. Kaskutas LA, Graves K. An alternative to standard drinks as a measure of alcohol consumption. J Subst Abuse 2000;12(1-2):67-78.
23. Kerr WC, Greenfield TK, Tujague J, Brown SE. A Drink Is A Drink? Variation in the Amount of Alcohol Contained in Beer, Wine and Spirits Drinks in a US Methodological Sample. Alcohol Clin Exp Res 2005;29(12):2015-21.
24. Beach. CSUL. California State University Long Beach.In, 2009.
25. O'Leary CM, Nassar N, Zubrick SR, Kurinczuk JJ, Stanley F, Bower C. Effects of dose, pattern, and timing of prenatal alcohol exposure on child behaviour problems. (Accepted for publication, Addiction, 2009).
26. Hepburn M. Substance abuse in pregnancy. Current Obstetrics & Gynaecology 2004;14(6):419-25.
27. Humphrey MD, Keating SM. Lack of antenatal care in far north Queensland. The Australian & New Zealand journal of obstetrics & gynaecology 2004;44(1):10-3.
28. Olegard R, Sabel KG, Aronson M, et al. Effects on the child of alcohol abuse during pregnancy. Retrospective and prospective studies. Acta Paediatrica Scandinavica Supplement 1979;275:112-21.
29. Burns L, Mattick RP, Cooke M. Use of record linkage to examine alcohol use in pregnancy. Alcoholism: Clinical and Experimental Research 2006;30(4):642-8.
30. Little BB, Snell LM, Rosenfeld CR, Gilstrap LC, 3rd, Gant NF. Failure to recognize fetal alcohol syndrome in newborn infants. American Journal of Diseases of Childhood 1990;144(10):1142-6.
31. Watson L, Blair E, Stanley F. Report of the Western Australian cerebral palsy register: to birth year 1999. Perth: Telethon Institute for Child Health Research; 2006.
32. Johnson JL, Leff M. Children of substance abusers: overview of research findings. Pediatrics 1999;103(5 Pt 2):1085-99.
33. Widom CS, Hiller-Sturmhofel S. Alcohol abuse as a risk factor for and consequence of child abuse. Alcohol Research and Health 2001;25(1):52-7.
34. Barber JG, Gilbertson R. The drinker's children. Substance Use and Misuse 1999;34(3):383-402.

35. Miller BA, Smyth NJ, Mudar PJ. Mothers' alcohol and other drug problems and their punitiveness toward their children. Journal of Studies on Alcohol 1999;60(5):632-42.
36. Dube SR, Anda RF, Felitti VJ, Croft JB, Edwards VJ, Giles WH. Growing up with parental alcohol abuse: exposure to childhood abuse, neglect, and household dysfunction. Child Abuse and Neglect 2001;25(12):1627-40.
37. Malpique C, Barrias P, Morais L, Salgado M, Pinto Da Costa I, Rodriques M. Violence and alcoholism in the family: how are the children affected? Alcohol and Alcoholism 1998;33(1):42-6.
38. Johnson CF. Does maternal alcoholism affect offspring? Clinical Pediatrics (Philadelphia) 1974;13(8):633-4.
39. Rao KN, Begum S, Venkataramana V, Gangadharappa N. Nutritional neglect and physical abuse in children of alcoholics. Indian Journal of Pediatrics 2001;68(9):843-5.
40. Egami Y, Ford DE, Greenfield SF, Crum RM. Psychiatric profile and sociodemographic characteristics of adults who report physically abusing or neglecting children. American Journal of Psychiatry 1996;153(7):921-8.
41. Wall A, Wekerle C, Bissonnette M. Childhood maltreatment, parental alcoholism and beliefs about alcohol: subgroup variation among alcohol-dependent adults. Alcoholism Treatment Quarterly 2000;18(3):49 - 60.
42. Nordberg L, Rydelius PA, Zetterstrom R. Parental alcoholism and early child development. Acta Paediatrica Supplement 1994;404:14-8.
43. Bower C, Silva D, Henderson TR, Ryan A, Rudy E. Ascertainment of birth defects: the effect on completeness of adding a new source of data. Journal of Paediatrics and Child Health 2000;36(6):574-6.
44. Harris KR, Bucens IK. Prevalence of fetal alcohol syndrome in the Top End of the Northern Territory. Journal of Paediatrics and Child Health 2003;39(7):528-33.
45. Allen K, Riley M, Goldfeld S, Halliday J. Estimating the prevalence of fetal alcohol syndrome in Victoria using routinely collected administrative data. Australian and New Zealand Journal of Public Health 2007;31(1):62-6.
46. Van Essen P, Gibson C, Scott H, Willoughby C, Chan A, Haan E. 2005 annual report of the South Australian Birth Defects Register; Incorporating the 2005 annual report of prenatal diagnosis in South Australia. Adelaide: Children, Youth, and Women's Health Service; 2008; 2008.
47. Elliott EJ, Payne J, Morris A, Haan E, Bower C. Fetal alcohol syndrome: a prospective national surveillance study. Archives of Disease in Childhood 2008;93(9):732-7.
48. Abel EL. An update on incidence of FAS: FAS is not an equal opportunity birth defect. Neurotoxicology and Teratology 1995;17(4):437-43.
49. Egeland GM, Perham-Hester KA, Gessner BD, Ingle D, Berner JE, Middaugh JP. Fetal alcohol syndrome in Alaska, 1977 through 1992: an administrative prevalence derived from multiple data sources. American Journal of Public Health 1998;88(5):781-6.

50. Bower C. Prevalence of FAS/FASD in Australia. In: WA Child and Youth Health Network, ed. Map of Australia showing prevalence rates based on a number of separate studies ed. Perth; 2009:1.
51. Coyne K, De Costa C, Heazlewood R, Newman H. Pregnancy characteristics of women giving birth to children with fetal alcohol syndrome in far North Queensland. Aust N Z J Obstet Gynaecol 2008;48:240-7.
52. Payne J, Elliott E, D'Antoine H, et al. Health professionals' knowledge, practice and opinions about fetal alcohol syndrome and alcohol consumption in pregnancy. Australian and New Zealand Journal of Public Health 2005;29(6):558-64.
53. Stoler JM, Holmes LB. Under-recognition of prenatal alcohol effects in infants of known alcohol abusing women. Journal of Pediatrics 1999;135(4):430-6.
54. Elliott EJ, Payne J, Haan E, Bower C. Diagnosis of foetal alcohol syndrome and alcohol use in pregnancy: a survey of paediatricians' knowledge, attitudes and practice. Journal of Paediatrics and Child Health 2006;42(11):698-703.
55. Applied Economics Pty Ltd. Cost description study of fetal alcohol spectrum disorder: Alcohol and Indigenous Programs Section, Drug Strategy Branch, Department of Health and Ageing; 2008 March 2008.
56. Lupton C, Burd L, Harwood R. Cost of fetal alcohol spectrum disorders. American Journal of Medical Genetics Part C: Seminars in Medical Genetics 2004;127C(1):9.
57. Streissguth AP. Fetal alcohol syndrome in older patients. Alcohol Alcohol Supplement 1993(2):4.
58. Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk Factors for Adverse Life Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects. Journal of Developmental and Behavioural Pediatrics 2004;25(4):11.
59. Fast DK, Conry J, Loock CA. Identifying Fetal Alcohol Syndrome Among Youth in the Criminal Justice System. Journal of Developmental and Behavioural Pediatrics 1999;20(5):3.
60. Rojas EY, Gretton HM. Background, offence characteristics, and criminal outcomes of Aboriginal youth who sexually offend: a closer look at Aboriginal youth intervention needs. Sex Abuse 2007;19(3):257-83.
61. Crime Research Centre. Crime and Justice Statistics for Western Australia: University of Western Australia; 2004.
62. Cox LV, Clairmont D, Cox S. Knowledge and attitudes of criminal justice professionals in relation to Fetal Alcohol Spectrum Disorder. Can J Clin Pharmacol 2008;15(2):e306-13.
63. Babor TF, Caetano R, Casswell S, Edwards G, Giesbrecht N, Graham K. Alcohol: No Ordinary Commodity - Research and Public Policy. Oxford and London: Oxford University Press; 2003.
64. Rose GA. Strategy of Preventive Medicine. Oxford; New York: Oxford University Press; 1992.
65. Loxley W, Toumbourou J, Stockwell T, Haines B, Scott K, Godfrey C. The prevention of substance use, risk and harm in Australia: a review of the evidence. Commonwealth of Australia; 2004.

66. Abel EL, Sokol RJ. Fetal alcohol syndrome is now leading cause of mental retardation. Lancet 1986;2(8517):1222.

67. Arendt R, Farkas K. Maternal Alcohol Abuse and Fetal Alcohol Spectrum Disorder: A life-Span Perspective. Alcoholism Treatment Quarterly 2007;25(3).

68. Bertrand J. Interventions for children with fetal alcohol spectrum disorders (FASDs): overview of findings for five innovative research projects. Res Dev Disabil 2009;30(5):986-1006.

69. Elliott E, Ridley G, Rose D, Morris A, Redmond D, Fowler J. Austrarlian Paediatric Surveillance Unit Ninth Annual Report 2001. Sydney: APSU; 2001; p. 32-4.

70. Bray DL, Anderson PD. Appraisal of the epidemiology of Fetal Alcohol Syndrome among Canadian Native peoples. *Can J Public Health* 1989;80(January/February):42-5.

71. Telethon Institute for Child Health Research. Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder: a Resource for Health Professionals (1st revision). Perth; 2009.

12. Glossary

ARBE	Alcohol Related Birth Effects
ARND	alcohol related neuro-developmental disorders
Apgar	Apgar assesses the health of newborn children immediately after birth and is determined by evaluating the newborn baby on five criteria on a scale from zero to two then summing up the values to give a resulting Apgar score which ranges from zero to ten. The criteria are colour, heart rate, grimace, activity and respiration.
AOD	Alcohol and other drug
CALD	Culturally and Linguistically Diverse
CACH	Child and Adolescent Community Health
CAMHS	Child and Adolescent Mental Health Service
CDS	Child Development Service
FAS	Fetal Alcohol Syndrome
FAE	Fetal alcohol effects
FASD	Fetal Alcohol Spectrum Disorder
Harmful drinking	Harmful drinking is defined as drinking at levels that are likely to cause significant injury or ill health
Microcephalic	Having an abnormally small head – head circumference less than the 3rd centile for gestation/age
WACHS	WA Country Health Service
WA	Western Australia

13. Appendices

Appendix One: Summary List of Recommendations

Below is a list of the recommendations listed in this Model of Care. However the recommendations should be read in conjunction with the associated text within the main document as this contains important details.

Recommendation 1:	Provide public education and community action to support responses to alcohol-related problems
Recommendation 2:	Prevent harmful alcohol consumption through responsible supply and service of alcohol
Recommendation 3:	Reduce harmful alcohol consumption by youth by addressing risk factors and promoting protective factors and resilience
Recommendation 4:	Promote healthy behaviour practices and pre-conception care for females of child bearing years including promotion of abstinence from alcohol prior to pregnancy
Recommendation 5:	Reduce unplanned pregnancy
Recommendation 6:	Improve access to antenatal and maternity services for disadvantaged groups
Recommendation 7:	Provide information to all pregnant women and their families about substance use and the risks associated with alcohol use during pregnancy including the recommendation for abstinence
Recommendation 8:	Establish protocols for the use of brief interventions addressing maternal alcohol use during pregnancy
Recommendation 9:	Increase collaboration between GPs, maternity and newborn service providers, alcohol and other drug services to ensure comprehensive drug and alcohol maternity services for all pregnant women, including those in rural and remote regions
Recommendation 10:	Identify gaps in the provision of antenatal care for women with alcohol-related dependency and develop state-wide protocols to ensure a streamlined process for accessing maternity services
Recommendation 11:	Screen for, and manage, alcohol withdrawal for pregnant women
Recommendation 12:	Refer pregnant and post-partum women with alcohol-related dependency to comprehensive health services addressing parenting and child and family wellbeing

Recommendation 13:	Implement opportunistic screening for alcohol consumption for all women of child-bearing age and the use of brief interventions where indicated
Recommendation 14:	Implement universal screening in pregnancy (first antenatal visit and each trimester) and the use of brief interventions where indicated
Recommendation 15:	Implement the routine collection of data on alcohol use during pregnancy for the Maternity and Child Health Information Division with annual reporting in the WA Perinatal Statistics Report
Recommendation 16:	Identify at risk newborns and children for further screening and possible FASD assessment
Recommendation 17:	Refer children with suspected FASD to appropriate assessment and intervention services
Recommendation 18:	Initiate consultation by Department of Health with Department of Health and Ageing, Divisions of General Practice and the Aboriginal Health Council of WA to consider the incorporation of screening for FASD into Medicare-funded child health checks and to develop clinical pathways and referral protocols
Recommendation 19:	Include screening for FASD in child health nurse screening assessments of children in the care of the Department for Child Protection
Recommendation 20:	Develop clinical pathways for screening and/or assessment of children of mothers attending drug and alcohol treatment services
Recommendation 21:	Work with magistrates and juvenile justice officers to support potential FASD clients
Recommendation 22:	Ensure FASD education resources and services are appropriate for individual communities
Recommendation 23:	Develop a multi-disciplinary FASD diagnostic service for children within the Child Development Service
Recommendation 24:	Develop clinical pathways for joint FASD assessment with other relevant health services and agencies
Recommendation 25:	Provide workforce training and development in FASD diagnosis for staff in regional centre
Recommendation 26:	Provide scheduled visits and use of telehealth by metropolitan based FASD assessment team to support regional centres
Recommendation 27:	Map referral pathways, existing clinical services and family support to identify gaps and develop additional resources as required

Recommendation 28:	Develop and implement treatment programs that support the child and strengthen their environment and support systems in order to maximise the child's potential as well as modify secondary effects
Recommendation 29:	Form an inter-agency FASD steering group supported by a reference group
Recommendation 30:	Ensure all relevant health professionals receive training and education on alcohol use, FASD and supporting healthy behaviour change
Recommendation 31:	Develop approved channels of agreed and confidential communication between sectors for any child diagnosed with FASD
Recommendation 32:	Develop data linkage ability between sectors to record, evaluate and share the health and other needs and service access of individuals with FASD
Recommendation 33:	Undertake further research to more accurately determine the prevalence of FASD in specific communities/regions and monitor changes in prevalence over time.

Appendix Two: Criteria for a Screening Test

- These criteria describe both the selection of a disease/condition, which may be appropriate for screening and the criteria for ranking the desirability/appropriateness of a screening method.
- The disease/condition selected should be of moderate to high severity i.e. associated with high risk of poor outcome if undetected.
- A population at risk should be identified.
- The natural history of the disease should be understood.
- There must be a sufficient time lag between the onset of the disease and the development of symptoms to allow a “window of opportunity” for screening.
- A screening test has been developed.
- Screening test method needs to be both sensitive and specific, to ensure a minimum number of false positive and false negative screening results.
- The screening method should be acceptable to the population.
- The financial costs of screening should compare favourably to the financial costs of treating the disease, if undetected, and its consequences.
- There should be facilities for assessment, diagnosis and rehabilitation.
- Treatment/intervention following early detection of disease needs to be available, accessible, acceptable and effective.
- There should be sufficient resources and processes for follow-up of all positive screen results in a timely manner.
- Screening programs should be a continuing process.

Screening analysis

Universal screening methods

Antenatal screening for alcohol consumption

Methods include audit tools and self-report screening questionnaires e.g. T-ACE, TWEAK.

Advantages

- Opportunity to provide support and intervention in pregnancy to reduce alcohol consumption
- Identification of at-risk infants at birth and opportunities for early intervention and prevention
- Low cost
- Easy to use
- Culturally appropriate
- Strong evidence-base

Disadvantages

- Expertise and sensitivity required to obtain reliable information from clients
- Potential stigma for women influencing health care in pregnancy
- Training and dissemination of information to health workforce is required
- Limited accessibility to support services for pregnant women with substance abuse issues in regional areas

Screening of newborns for Fatty acid ethyl esters in meconium

Advantages

- There is a major advantage in the potential to identify individuals early in the course of FASD, therefore maximizing the opportunities for early intervention and prevention of subsequent alcohol-exposed pregnancies.
- General population already accepts universal neonatal screening for biological markers of disease by blood sampling (Guthrie and metabolic screening test)
- Neonates usually remain in health care settings for 24 hours, which is the time period required for most infants to pass meconium.

Disadvantages

- The technology required for meconium testing is not available in pathology facilities at the Women's and Children's Health Services.
- Health professionals in both public and private settings would require training in meconium sampling and the screening protocol.
- Additional laboratory costs involved in meconium testing, which warrants cost-benefit analysis.
- Ethical considerations required in obtaining informed consent from parents.

Screening of newborns via Linkage of a potential FASD database with Midwives Notification Database

Advantages

- There is a major advantage in the potential to identify individuals early in the course of FASD, therefore maximizing the opportunities for early intervention and prevention of

Disadvantages

- Screen positive criteria of small-for-gestational age will be associated with high sensitivity for FAS, but low specificity and therefore, low positive predictive value. The screening test

subsequent alcohol-exposed pregnancies.

- Collection of data by midwives already occurs throughout the state as a standard practice. Data recorded includes gestation, birth weight, length and birth head circumference – therefore, there would be minimal additional cost to achieve improved data linkage and detection of screen-positive cases.
- Linkage would allow identification of infants <2500g, SGA or whose birth head circumference was <3rd C adjusted for gestation (microcephaly). These are biomarkers for FAS.

may not show high sensitivity for FASD.

- Screen positive criteria of congenital microcephaly will be associated with high sensitivity, but lower specificity. This criterion may not have high sensitivity for FASD.
- The screening pathway will require additional resources for follow-up of both true and false-positive individuals, and training of the medical workforce in diagnosis of FAS.

Infant and Preschool screening methods

Measurement of growth parameters by health professionals. Screen-positive defined as height, weight or head circumference below the 10th C.

Advantages

- Desirability of identifying individuals early in the course of the condition.
- Tests are easy to perform.
- Screening method is likely to have high acceptability by the general population as it is not associated with adverse effects for the child and is a low cost test.
- Sensitivity of using growth deficiency as a marker of FAS is likely to be high.
- Possibility of linking this activity to the infant immunisation schedule for contact at 12-18 months of age and at 4 years or with the Medicare funded child health checks (current items include an annual health check for Indigenous children and a 4 year old health check by general practitioners).

Disadvantages

- The cut-off value of the growth below the 10th C will be associated with low specificity for FAS.
- Additional resources are required for follow-up of both true and false-positive cases.
- The criterion of growth deficiency may not be present in FASD.
- Detection of FAS at 4 years is less desirable than in infancy due to missed opportunities for early intervention and secondary prevention, however, still more desirable than detection at an older age due to the opportunity for appropriate educational intervention, secondary prevention and family support.

Developmental screening in infancy

Methods include the use of parent questionnaires such as the Parent Evaluation of Developmental Status (PEDS), Ages and Stages Questionnaire (ASQ 0-6years) and the Ages and Stages Social-Emotional Questionnaire (ASQ-SE).

Advantages

Disadvantages

- Desirability of identifying individuals early in the course of the condition.
- Tests are easy to perform.
- Screening method is likely to have high acceptability by the general population as it is not associated with adverse effects for the child and is a low cost test.
- Child Health nurse workforce has already received training in administering these screening tools.
- Child and Adolescent Community Health is currently implementing screening using the PEDS questionnaire for all children at age 3-4 months, 8 months, 18 months, 3 years and again at school entry (4-6 years). Children who screen positive are then offered second stage screening with the ASQ (0-6 years).
- Referral pathways already exist for further assessment of screen positive children by Child Development Services.

- While there is a recommended Universal Contact Schedule (2006) for infant visits to Child Health Nurses, the program is voluntary and has low participation.
- Screening instrument is non-specific for FASD.
- Access to Child Health Nurses may be limited in some regional and remote areas.
- The screening instrument (ASQ 0-6) has not been adapted for use in indigenous communities.

Screening in Early Childhood for development difficulties/delays:

Screening of children on enrolment in full-time education (age 5 years):

Screening by child health nurses using the PEDS and the Ages and Stages questionnaires.

Advantages

- High proportion of population comply with compulsory education.
- Identifies children early in educational course in order to program educational interventions.
- Good sensitivity for screening instrument.
- High acceptability – screening by Child Health Nurses already accepted for vision/hearing.

Disadvantages

- Failure to identify children before 4 ½ - 5 years misses opportunities for early developmental intervention.
- Also may miss opportunity to prevent heavy alcohol consumption in subsequent pregnancies if pregnancy spacing is at intervals less than 4 years.
- Ages and Stages screening tool requires translation into languages other than English.
- Paper based questionnaire may not be suitable for parents with low literacy skills.
- Screening tool is non-specific for FASD.

- Number of positive screens may overwhelm child development services and diagnostic services.

Screening by digital facial photography and growth measurements

Advantages

- Facial features are highly specific for FAS.
- Non-invasive medical investigation.
- Likely to be acceptable to parents.
- Relatively low expertise required to take photos.
- Screening instrument has proven high sensitivity and specificity in a high-risk population.
- Screening could be incorporated into a school entry health assessment by the school health nurse.
- Timing of screening is early in the child's educational course, and therefore, diagnosis at this stage would allow appropriate educational intervention.

Disadvantages

- Costs: equipment costs for digital cameras.
- Staff would require training in techniques of digital photography.
- Time required for analysis of photos by paediatrician.
- Unknown cultural security for Indigenous and CALD sub-populations.
- The acceptability of digital facial photography in low-risk populations is unknown.
- Infrastructure required for storage of data.
- Likely to miss broader spectrum of FASD.
- Problems with lack of ethnic norms (e.g. Australian Indigenous subpopulation).

Appendix Three: FASD Reference Group List

Aboriginal Community Controlled Health Organisations (ACCHOs)

Commissioner for Children and Young People

Consumers including the birth parents/carers/individuals with FASD

Department for Child Protection

Department for Communities

Department of Corrective Services

Department of Education and Training

Department of Health – relevant health services*

Department of Housing

Department of Justice

Disability Services Commission

Divisions of General Practice

Education and research institutions

Employment service providers

Foster Carers Association

Local government authorities

Non government agencies

Ord Valley Aboriginal Health Service FASD Project

Other private and commercial organizations as identified

Private health practitioners

WA Liquor Licensing Authority

***Department of Health services:**

- Statewide Maternity and Newborn Services, Obstetricians, Midwives, Maternity Hospitals
- Drug and Alcohol Office, including community drug service teams
- Child and Adolescent Health Service
- WA Country Health Service Population Health Unit
- Office of Aboriginal Health
- Mental Health Services

Appendix Four: Audit-C Screening Tool

Sourced from the WA Drug and Alcohol Office (WA Health)

Drug and Alcohol Office

Department of Health
Government of Western Australia
WA Country Health Service

MRN sticker here

AUDIT-C Alcohol Screen

Each of these is a standard drink

Full Strength Beer
285ml Middy
4.9% Alc./Vol

Mid Strength Beer
375ml
3.5% Alc./Vol

Spirit Nip
30ml
40% Alc./Vol

Small Serve of Wine
100mL
12% Alc./Vol

Please tick the box next to your answer.
If your answer falls between two boxes, tick (✔) the box to your right

Are you...
☐ Male
☐ Female

AGE GROUP

☐ Under 20 ☐ 20-29 ☐ 30-39 ☐ 40-49 ☐ 50-59 ☐ 60-69 ☐ 70+

	SCORE
1. How often do you have a drink containing alcohol? ☐ never ☐ monthly or less ☐ 4 times a month ☐ 2 to 3 times a week ☐ 4 or more times a week	☐
2. How many 'standard' drinks containing alcohol do you have on a typical day when you are drinking? ☐ 1 or 2 ☐ 3 or 4 ☐ 5 or 6 ☐ 7 to 9 ☐ 10 or more	☐
3. How often do you have six or more standard drinks on one occasion? ☐ never ☐ less often than monthly ☐ monthly ☐ weekly ☐ daily or almost daily	☐
TOTAL	☐

Other common drink servings

1.5 drinks
Alcoholic Soda
340mL
5.5% Alc./Vol

36 drinks
Cask Wine
4L
12% Alc./Vol

1.5 drinks
Full Strength Beer
375mL
4.9% Alc./Vol

24 drinks
Bottle of Spirits
750mL
40% Alc./Vol

0.8 drinks
Light Beer
375mL
2.7% Alc./Vol

7 drinks
Bottle of Wine
750mL
12% Alc./Vol

How to score and interpret the AUDIT C

AUDIT C is a short version of the World Health Organisation Alcohol Use Disorders Identification Test (AUDIT). AUDIT C is an effective (reliable) screening tool for detecting risky or high risk drinking patterns.

Scoring Audit C

- The **AUDIT C** questions are scored from left to right
- The questions are scored on a five-point scale from 0, 1, 2, 3, and 4.
- Record the score for each question in the score box on the right even if it is a zero (0) score.
- Add each score then record a total score in the **TOTAL** box at the bottom of the page.
- The maximum score is 12.

Interpreting and understanding the AUDIT C score

A score of 0-3 (females) and 0-4 (males) indicates a **'low risk'** pattern of drinking.
Suggested intervention: Provide preventative advice to encourage 'low risk' drinking.
See Table 1.0 'Low Risk' for intervention and feedback.

A score of 4-7 (females) and 5-7 (males) indicates a **'risky'** pattern of drinking.
Suggested intervention: Provide a brief intervention (BI) including feedback on score and advice for reducing alcohol related health risks.
See Table 1.0 'Risky' for intervention and feedback.

A score of 8+ (both females and males) indicates a **'high risk'** pattern of drinking.
Suggested intervention: Provide a brief intervention (BI) including feedback on score and active advice and refe to specialist AOD or medical services.
See Table 1.0 'High Risk' for intervention and fee

Cautions:

1. Any intervention outlined below may need to be modified based on a client/patients previous history of treatment for alcohol-related problems or dependence.

Table 1.0 AUDIT C Guide for suggested intervention and feedba

AUDIT C Total score Females	AUDIT C Total score Males	Risk level	Guide for intervention & feedback
0 - 3	0-4	Low risk	• Discuss AUDIT C score • Provide feedback to encourage further 'low risk' drinking • Give: 'Alcohol and your health' booklet • Discuss specific benefits for low-risk drinking as needed

4 - 7	5-7	Risky	• Discuss AUDIT C score
			• Provide feedback for 'low risk' drinking
			• Use 'Here's to your health booklet' to discuss:
			  • Benefits of low-risk drinking
			  • Tips to cutting down
			May also be useful to discuss:
			• Importance and confidence for cutting down.
			• An action plan for cutting down (if needed).
			• Follow-up and referral (if needed).

8+	8+	High Risk	**Requires active referral and intervention** • Discuss AUDIT C score **Actively refer to GP or Community Drug service Team (CDST).** **Discourage abstinence. Explain the need to cut down use under medical supervision.** • Arrange a follow-up session May also be useful to discuss: • Importance and confidence for taking action • Undertake further assessment to identify others risks or harms • Use 'Here's to your health booklet'

taff Use Only

Intervention _____

Intervention Level

☐ Low risk ☐ Risky ☐ High Risk

☐ No intervention

Referral Made

☐ G.P. ☐ CDST ☐ Other

Appendix Five: Australian Standard drinks

Australian standard drinks[71]

The Australian Standard Drink measure contains 10g of alcohol.

Appendix Six: List of Drug and Alcohol Services[71]

Current list can be obtained from the Telethon Institute for Child Health Research (appendix in booklet) - http://www.ichr.uwa.edu.au/alcoholandpregnancy

Further information

Alcohol and Pregnancy Research Group, Telethon Institute for Child Health Research
www.ichr.uwa.edu.au/alcoholandpregnancy Ph: (08) 9489 7777

Australian Paediatric Surveillance Unit
www.apsu.org.au Ph: (02) 9845 3005

National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD)
NOFASARD is a nationwide service providing support for parents and carers of children or adults with FASD, information and advocacy about FASD.
www.nofasard.org Mobile 0418 854 947

Alcohol Drug and Information Services

Alcohol & Other Drugs Treatment Services National Directory
www.aodservices.net.au

Australian Capital Territory (Alcohol and Drug Program)	Ph: (02) 6207 9677 (24 hrs)
New South Wales (ADIS)	Ph: 1800 422 599 (24 hrs)
New South Wales (Drug and Alcohol Specialist Advisory Service)	Ph: 1800 023 687
Northern Territory (ADIS)	Ph: (08) 8922 8399
Queensland (ADIS)	Ph: 1800 177 833 (24 hrs)
South Australia (ADIS)	Ph: 1300 131 340 (24 hrs)
Tasmania (Alcohol and Drug Service)	Ph: 1800 888 236 (24 hrs)
Victoria (Direct Line ADIS)	Ph: 1800 888 236 (24 hrs)
Western Australia (ADIS)	Ph: 1800 198 024 (24 hrs)

Useful resources

Telethon Institute for Child Health Research
Resources for use by health professionals to support their advice to women about alcohol use in pregnancy and Fetal Alcohol Spectrum Disorder:

- 32 page booklet for health professionals
- Fact sheet for health professionals
- Wallet cards for women *No Alcohol in Pregnancy is the Safest Choice.*

To download or to order these resources, please go to the Telethon Institute for Child Health Research, Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder website:
http://www.ichr.uwa.edu.au/alcoholandpregnancy

Australian Guidelines to Reduce Health Risks from Drinking Alcohol
www.nhmrc.gov.au/publications/synopses/ds10syn.htm

Fetal Alcohol Syndrome: A Literature Review
www.health.gov.au/internet/wcms/publishing.nsf/Content/health-pubhlth-publicat-document-fetalcsyn-cnt.htm/$FILE/fetalcsyn.pdf

Rural Health Education Foundation
Fetal Alcohol Spectrum Disorder (also on DVD)
www.rhef.com.au/programs/614/614.html
Drinking for Two? (also on DVD)
www.rhef.com.au/programs/708/708.html

Delivering a **Healthy WA**

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