Introduction

Foetal alcohol spectrum disorder (FASD) is a diagnostic term used to describe the range of mental and physical effects on a developing unborn baby that are caused by drinking alcohol during pregnancy (1). There is no cure for FASD so prevention is critical for improving the health of children. Due to previous limitations in diagnosis of FASD, there are few accurate estimates of the prevalence in Australia, but it is generally believed that the rate is higher among Aboriginal and Torres Strait Islander communities than in the general population.

The Alcohol and Other Drugs Knowledge Centre contains a collection of resources relating to FASD in Aboriginal and Torres Strait Islander communities. The FASD portal workforce section provides information on training and skill development opportunities including training in using alcohol use screening tools and brief intervention.

The FASD portal provides a platform for researchers to promote their findings and makes evidence-based information readily available to all those working to prevent and manage FASD in their communities.

Diagnosis and expression

Alcohol consumption by a pregnant woman alters the normal development of the foetus, which can result in a spectrum of characteristics such as: brain damage, poor growth, birth defects and learning problems, known as FASD (2). Babies who have been exposed to alcohol during pregnancy may exhibit characteristics including restlessness, poor feeding, low birth weight, and sensitivity to light, noise and touch (2).

Children diagnosed with FASD may display certain characteristic facial features such as a thin upper lip and a smooth philtrum. Learning difficulties like problems with memory, language development, motor skills and impulse control may also be evident in these children (1, 2), however, many of the learning difficulties associated with FASD do not become apparent until a child is older (2, 3).

Prevalence

Previously a lack of awareness of FASD and the absence of a national diagnostic criteria has made estimating the prevalence of FASD in Australia uncertain (4).

Various studies using data from states and territories have estimated rates at 0.01 to 1.7 per 1000 births in the total population (4). Internationally, estimates of FASD range from 2.0 to 7.0 per 1000 in mainstream populations, with prevalence higher in vulnerable populations (5).
Prevalence in Aboriginal and Torres Strait Islander populations

Rates of FASD for the Aboriginal and Torres Strait Islander population have previously been estimated in the range of 0.15 to 4.70 per 1000 births (4). However, given the limitations already outlined in collecting information on FASD, it is generally accepted that these figures are likely to underestimate the prevalence of FASD in Australia (4).

A 2015 study has found very high rates of FASD in some remote communities in the Fitzroy Valley, Western Australia (WA), with the number of cases diagnosed at 120 per 1000 for children born between 2002 and 2003 (6).

Research is being conducted at the Telethon Institute to determine the extent of FASD among inmates within the prison system. For example, a study at Banksia Hill Detention Centre currently being undertaken in WA by the Telethon Kids Institute reported preliminary findings of high rates of FASD within youth detention, with at least one in three young people assessed as having FASD (7, 8).

Need for prevention

The risk of FASD increases with the amount of alcohol a pregnant woman consumes—the highest risk occurs when pregnant women frequently consume high levels of alcohol (9). However, lower levels of drinking at critical times while the foetus is developing, have also been linked with harm to the developing foetus (1, 9).

As there is no specific treatment or cure for FASD, it is critically important to prevent FASD and to prevent the lifelong burden borne by individuals and families (10).

The current Australian guidelines to reduce health risks from drinking recommend that for women who are pregnant or planning a pregnancy, not drinking is the safest option (9).

Guideline 4: Pregnancy and breastfeeding states (9, p. 67):

Maternal alcohol consumption can harm the developing foetus or breastfeeding baby

A. For women who are pregnant or planning a pregnancy, not drinking is the safest option.

B. For women who are breastfeeding, not drinking is the safest option.

However, conflicting messages in the media and even within health services, mean it is unclear if the message to avoid alcohol is being effectively communicated to pregnant women or women who are planning a pregnancy (11).

Policy response, funding, expansion of research, and dissemination of resources

Until recently, limited training opportunities for health professionals and the lack of a nationally adopted diagnostic instrument were persistent barriers to early diagnosis and appropriate management and prevention of FASD (1).

Awareness of FASD has grown—from a time when a handful of dedicated community members, carers and health workers advocated for the need to recognise FASD, to 2012 when a Parliamentary Inquiry was initiated into developing a national approach to the prevention, intervention and
management of FASD in Australia (2). The Inquiry led to 19 recommendations being made, which then culminated in a national FASD action plan (2, 12).

From this action plan a number of actions have flowed, including:

- an agreed-upon national diagnostic criteria for FASD supported by training and resources on how to use the diagnostic criteria (1)
- increased funding toward:
  - raising awareness among health workers to use routine screening practices to assess for alcohol use
  - resources to support health workers to talk to women about alcohol consumption and recognise and respond to women at risk (1, 2).

The increase in availability of resources and publications about FASD and the development of a diagnostic tool has resulted in a need for a readily accessible repository of practice and health promotion information.

The disproportionate effect FASD has had, and continues to have, on Aboriginal and Torres Strait Islander communities indicates a need for culturally appropriate approaches that are effective in preventing and responding to FASD in Aboriginal and Torres Strait Islander people.

**Australian Indigenous AOD Knowledge Centre**

The Australian Indigenous Alcohol and Other Drugs Knowledge Centre (Knowledge Centre) is a free web resource that offers comprehensive, culturally appropriate information on all forms of substance use.

The Knowledge Centre web resource is managed by the Australian Indigenous HealthInfoNet. It is supported by, and works in collaboration with three national research centres; the National Centre for Education and Training in Addiction (NCETA), the National Drug Research Institute (NDRI) and the National Drug and Alcohol Research Centre (NDARC).

It has a particular focus on supporting the information needs of both health practitioners and community members, with the aim of providing evidence based information to reduce harms from alcohol and drug use in Aboriginal and Torres Strait Islander communities. The Knowledge Centre provides information on alcohol, illicit drugs (including kava), pharmaceuticals and volatile substances with a specific section focussing on FASD (the FASD portal).

**How the FASD Portal can support workers**

The FASD portal provides a central collection of resources relevant to FASD in Aboriginal and Torres Strait Islander communities. Content for the portal is guided by the Knowledge Centre’s national reference group and includes:

- key facts
- policies and strategies
- publications
• health promotion resources
• health practice resources
• programs and projects
• organisations
• workforce information.

Key facts provide a plain language overview of information on FASD including:
• diagnosis
• prevention
• management
• examples of programs that are addressing FASD and alcohol use in pregnancy.

Policies and strategies
The section on policies and strategies provides a collection of policies that address FASD at both a state and national level.

Publications
The publications section is a unique collection of FASD publications with an emphasis on Australian content that is particularly relevant to Aboriginal and Torres Strait Islander people. The collection includes the most recent material (the last 7 years of publications) and is constantly being updated. It includes key references, conference presentations, journal articles and other literature on specific topics of prevalence, prevention and treatment, and the health and social impacts of FASD.

User survey statistics for the Knowledge Centre from 2015 to 2016 have shown that approximately 60–80% of users find the FASD portal to be useful or very useful.

Source: AOD Knowledge Centre user survey 2015-2016
Overall, health promotion and health practice resources on the Knowledge Centre are consistently identified in user surveys as being useful or very useful by approximately 92% of users.

<table>
<thead>
<tr>
<th>Year</th>
<th>Very useful/useful</th>
<th>Not useful</th>
<th>Didn’t know</th>
<th>Don’t use</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2016</td>
<td>70%</td>
<td>10%</td>
<td>10%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Source: AOD Knowledge Centre user survey 2015-2016

**Health promotion resources**

The Knowledge Centre hosts a collection of FASD health promotion resources. The 60 or more culturally appropriate resources come in a variety of formats including videos, booklets, posters and radio broadcasts. Many of these resources are relevant to community settings or for working in Aboriginal health services.

Videos such as *Strong Boorais, bright futures* produced in collaboration between the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) and the Australian Drug Foundation (ADF) showcase stories encouraging mothers, fathers and families to give their baby the best start in life and seek help to stop alcohol and other drug use during pregnancy and breastfeeding (13). Other resources such as the New South Wales *Stay strong alcohol and pregnancy* series—a suite of booklets, videos and posters—provide valuable information support to clinicians and community members working to raise awareness and prevent FASD.

**Health practice resources**

Health practice resources contain key health practice guidelines relevant to FASD including the recently published *Australian guide to the diagnosis of FASD*. Published in 2016, the guide provides clinicians with national diagnostic criteria for FASD to help facilitate and standardise the diagnosis of FASD within Australia.

Other important health practice resources in this section are:

- WA Health Audit-C learning guide—a guide for midwives and other health professionals on how to use Audit-C as a screening tool (14)
- information on what is a standard drink (15)
• practice guidelines for workers, using a brief intervention model to yarn with women about alcohol use (16).

Research has shown that early recognition of FASD and intervention has a positive impact in helping the individual to reach their potential and minimise adverse outcomes later in life (1, 17). It is therefore important to not only widely disseminate information on practice guidelines such as the national diagnostic criteria but also make material available on how to support children who are living with FASD. The FASD health practice resources includes practical resources for educators, carers and health workers on supporting children with FASD in different settings (18, 19).

Emerging health practice resources (such as the FASD prevention and health promotion resources being developed by Menzies School of Health Research), are uploaded to the FASD portal as they are published, thus ensuring that even the most recently developed support materials are made freely available to a wide audience.

Programs
Comments from user surveys for the AOD Knowledge Centre reflect the value of having a web resource with comprehensive information on programs and organisations, which allows practitioners, including managers to map and identify services.

‘I undertake AOD catchment planning and have a series of background documents which I regularly update as I become aware of new resources…’

The Knowledge Centre user surveys for 2015-16 found approximately 24% of users surveyed reported using the Knowledge Centre for developing programs.

The programs section on the FASD portal captures the range of work being done by communities to prevent and address FASD, including programs that offer clinical support and descriptions of research being done in this area. Programs such as Marulu: the Liliwan Project show how women from the Marninwarntikura Women’s Resource Centre initiated the Liliwan Project in 2008 and are working in partnership with researchers from the George Institute, the University of Sydney and Telethon Kids Institute to study the incidence and prevalence of FASD in the Fitzroy Valley, Western Australia.

This section also has categories devoted to: education; and FASD justice programs which documents research and other programs such as court diversion relevant to FASD.

The FASD programs section includes both completed and current programs and where available, any related publications and evaluations of programs are provided, strengthening the evidence base for practice.

Workforce
Research has identified that health professionals may lack confidence in: asking about alcohol use during pregnancy; providing advice about the effects of alcohol use in pregnancy; and assisting with reducing or stopping alcohol use (20-23).

The FASD portal workforce section provides information from across Australia on current training and skill development opportunities to support the workforce to learn more about FASD. These include training in alcohol use screening tools and brief intervention, as well as finding out where to go for family support. A range of conferences, events and courses specific to FASD are also listed.
The Knowledge Centre user surveys 2016 indicated that approximately 32% of users reported continuing professional development as a reason to use the Knowledge Centre.

Table 1  Top 3 reasons reported by users for using the Knowledge Centre: Knowledge Centre Survey May 2016 – November 2016

<table>
<thead>
<tr>
<th>May 2016</th>
<th>Percentage</th>
<th>November 2016</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Browsing information</td>
<td>67%</td>
<td>Browsing information</td>
<td>75%</td>
</tr>
<tr>
<td>Learning about AOD and related issues</td>
<td>41%</td>
<td>Learning about AOD and related issues</td>
<td>43%</td>
</tr>
<tr>
<td>Continuing Professional Development</td>
<td>35%</td>
<td>Continuing Professional Development</td>
<td>30%</td>
</tr>
</tbody>
</table>

Implications of FASD portal for services

The prevalence of FASD is high in some Aboriginal communities and children who are born with FASD have an increased risk of coming in contact with the criminal justice system later in life (6, 24). Young people with FASD may have difficulties engaging with school, be more likely to be unemployed and have a higher risk of having becoming involved with the justice system (7). The disabilities commonly involved in FASD that include difficulties in understanding cause and effect, impulsiveness and a vulnerability to being coerced by others become risk factors for offending and disrupted education and employment.

If the preliminary results from the Banksia Detention Centre study are confirmed, the presence of FASD within our prison population could have profound implications for the management and sentencing of detainees (8, 25). In particular it points to the urgent necessity for a prevention strategy for FASD and for more effective solutions than prison for people who are struggling with the lifelong disability that is FASD.

The high rates of FASD reported in some Aboriginal communities also indicate that preventing FASD needs to be addressed on many levels. For families caring for a child with FASD, the earlier they receive appropriate support, the better the outcome for the individual, the family and the community (26).

By making information readily available to health workers, the FASD portal seeks to raise awareness of FASD to support workers to:

- identify skill development opportunities in relation to FASD
- incorporate regular screening and assessment in to their work with clients
- support women to make informed decisions about their alcohol use and
- alert people about the issue of FASD in the community.

Conclusion

The FASD portal provides a platform for researchers to promote their findings, and services to share information, so that effective measures to reduce the incidence of FASD and strategies for improving the life chances for individuals suffering from FASD, can be shared with health workers, carers and policy makers.
In this way the FASD portal seeks to contribute to providing the evidence base to prevent and reduce FASD in the community.

References


11. Crawford-Williams F, Steen M, Esterman A, Fielder A, Mikocka-Walus A. ‘If you can have one glass of wine now and then, why are you denying that to a woman with no evidence’: knowledge and practices of health professionals concerning alcohol consumption during pregnancy. Women and Birth. 2015;Articles in Press(http://dx.doi.org/10.1016/j.wombi.2015.04.003).


Presenter

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