Fetal Alcohol Spectrum Disorder (FASD) Prevention for Community Drug Action Teams

The Australian Drug Foundation
Introduction

This report aims to inform the development of a toolkit for Community Drug Action Teams to then better inform community based initiatives in the prevention of fetal alcohol spectrum disorders. It is often said but less often actioned, that we live in a society which ‘loves’ alcohol and there is no doubt that the prevention of FASD, like all other harms attributable to alcohol are complex. In response, planners need to acknowledge the complexity and recognise that raising awareness does not necessarily equate with changing attitudes to alcohol consumption nor behaviour.

The FASD literature reveals limited evaluation of the relative effectiveness of community based prevention activities to achieve these changes when raising awareness is the sole objective. Most FASD prevention to date is based on practical wisdom and the general disability literature with “very little information available on evidence-based practices”1 and however well-intentioned and important, 40 years of raising awareness has not resulted in sustained change.

Sharing evidence based information increases knowledge and importantly, provides the opportunity to de-mythologise some of the messages imparted by others. Clear information can lead to informed decision making and ultimately may change attitudes and behaviours. In respect to FASD prevention, women (and girls) continue to be the primary target group for change however girls and women should not shoulder this sole burden for the prevention of FASD nor should we just actively express our interest in girls and women’s overall health and wellbeing during pregnancy. Secondly, the focus on girls and women who drink in pregnancy has been on the high risk end of the spectrum with little attention to those who consume alcohol at less risky levels.

Pregnant women at risk for alcohol use and those affected with FASD, invariably are in contact with a cross-sector range of service providers and provide opportunities for education and interventions to reduce the risk of FASD. It is often an overlooked and yet salient point, that the majority of women are influenced by the choices made by partners, family and/or friends and this influence can be positive in supporting better choices. Prevention therefore needs to consider the environments in which pregnant women are using alcohol. Pregnancy is a time when the community must embrace the physical, emotional and psychosocial investment women make and women do not need the additional stress of our indignation that they should be doing better, doing more and/or doing it differently. As a community, we should be wrapping pregnant women in support and discovering new ways to share responsibility.

In this background report, a selection of activities is presented with some proposals about why these activities work or don’t work, whether these activities show promise or if improvements might make a difference. Most are adaptable to different local and regional contexts and importantly are gender neutral and reflect the need for a broader strategy within which sub strategies or activities can be implemented which contribute to this overall aim.

Participation in evaluation (what worked, what did not work and what is learned in the process) is therefore vital to building prevention knowledge in the future. Communities that engage in FASD prevention and therefore play an active part in building this body of work.

Vicki Russell
FASD Consultants Australia

---

FASD in Australia

Fetal Alcohol Spectrum Disorders (FASD) describes a variety of permanent physical, intellectual and developmental disabilities that can occur in children attributable to the mother’s consumption of alcohol (a known teratogen) during pregnancy. These conditions vary from mild to very severe, and a diagnosis is made accordingly (Newcastle FASD Strategy 2015).

The prevalence of Fetal Alcohol Spectrum Disorder in Australia is currently unknown however, the prevalence “of the disorders associated with FASD...among younger school-aged children has been estimated to be up to 2% in the United States, and up to 5% in Italy (May et al. 2009).”

There is a dose-response relationship throughout pregnancy between the pattern of alcohol use and the level of fetal harm. Alcohol is quickly absorbed into blood stream and crosses the placenta meaning the blood alcohol level (BAL) of the pregnant woman and unborn child is roughly equal.

Science informs that any alcohol in pregnancy is a risk, that there is no known minimal use of alcohol to not cause fetal harm. The reality is that there is no predictor of which pregnancy or fetus may be vulnerable to the teratogenic effect of alcohol in pregnancy.

FASD Diagnosis

In May 2016, the Australian government endorsed new Australian guidelines for the diagnosis of FASD. As explained in the Australian Guide to the Diagnosis of FASD, the concept of Fetal Alcohol Spectrum Disorder has been adopted as a diagnosis.

For a diagnosis of FASD, an individual must have prenatal alcohol exposure and severe neurodevelopmental impairment in at least three of ten specified domains of central nervous system structure or function. The overarching diagnostic term of FASD simplifies the terminology and emphasises the primary importance of the severe neurodevelopmental impairment that results from an acquired brain injury caused by alcohol exposure before birth. Within FASD are two sub-categories: FASD with three sentinel facial features (similar to the previous diagnostic category of Fetal Alcohol Syndrome); and FASD with less than 3 sentinel facial features (which encompasses the previous diagnostic categories of Partial Fetal Alcohol Syndrome and Neurodevelopmental Disorder-Alcohol Exposed).

---


FASD is a brain based condition

Primary conditions are those that most clearly reflect underlying changes in brain structure and function. There is wide variability from individual to individual and cross over between the following areas:

Executive functioning – planning, predicting, organising, prioritising, sequencing, initiating and following through. For adults, there may be difficulty in setting goals, complying with contractual obligations, being on time, adhering to a schedule.

Memory – taking in and understanding information, forming associations, memory recall and responses. The individual might experience problems learning from past mistakes and often the same mistakes are made over and over again despite increasingly severe consequences. Memory might also be inconsistent in that a task that can be recalled for two days is then forgotten on the third day.

Adaptive functioning impacts on daily life, managing all of the tasks needed to be achieved including self-care.

Abstraction – understanding the concept of time, understanding mathematical concepts and/or the value of money

Judgement – making decisions, recognising danger or distinguishing danger from safety, friend from stranger, fantasy from reality

Communication and language – forming links and associations, applying a learned rule in different settings, understanding instructions and giving agreement or consent, comprehending the meaning of language and accurately answering questions, talking excessively and engaging in meaningful exchange with others, processing speed with accuracy.

Social communication – relating to peers, reading social cues (verbal and non-verbal) and social rules

Perseveration – rigid, stuck, have problems switching thoughts, stopping activities or transforming to a new task, react strongly to changes in setting, program or personnel

Dysmaturity - social, emotional and cognitive ability appropriate to age may be at a much younger developmental age. A 5-year-old may be developmentally more like a 2-year-old, a 12-year-old like a 6-year-old, and a 25-year-old more like a 13-year-old and so on.

Impulsivity – acts first and may or may not be able to see the problem after the action

Sensory systems – over-reacts to stimuli, for example will not like physical touch, overwhelmed by sensory input - unable to filter out extraneous stimuli or under-reacts to pain and not complain of earaches, broken bones, and be unable to experience painful stimuli like heat or cold.
Community Prevention

If you imagine the problem of FASD as a river, those living with the condition can be thought of as ‘downstream.’ For this group of individuals, the problem is real and it is impacting on all facets of life for each person and their family or support system. Just as it is important to support and understand the needs of those living with FASD, your community might need to figure out where best to prevent the problem before it begins. In this case, the focus will be ‘upstream’ to the source of the river flow, or in the case of FASD, to where the problem began.

In developing community strategies, it is important to note that individual and community awareness “can be improved through education that must engage women, men and children; be culturally sensitive; be informed by community knowledge, attitudes, values and drinking practices; and be consistent with national guidelines.” Further, an understanding of the causal pathway to drinking in pregnancy in primary prevention is deemed essential with no distinction based on economic status or residential address. Successful campaigns are therefore “carefully planned, used multiple strategies, focused on a specific problem, used carefully selected messages and images, had good reach and considered current levels of awareness.”

Successful campaigns focused on large populations and were designed for populations at lower risk.

As the diagram below suggests, prevention at any point can always lead to better outcomes. Alcohol use occurring pre-confirmation of pregnancy is a risk when 50% of pregnancies are reported to be unplanned. Most women stop drinking once pregnancy is confirmed but realization can make for a stressful time. For this population group, planning for pregnancy with their partner is the key. For others, stopping alcohol use is more difficult and community support is crucial.

---

A chosen priority might be to raise awareness with an aim at changing community attitudes and behaviours to alcohol use in pregnancy or it could be to bring a focus to support for those living with FASD, their parents and building the capacity of service providers? It might be that both can be achieved. Each group will need to determine what is in the best interest of their respective community and what is practical within a range of options will also consider the limitations of available resources.

The following ten points are drawn from the available literature. This list is not exhaustive however may provide some guidance in the development of FASD community prevention projects. Alcohol use and misuse can prove to be a multi-faceted problem and a challenge for communities. Likewise, FASD is a complex problem with cross system consequences in health, social, finance and justice.

1. To begin, a needs analysis in the form of a group brainstorm might be a worthwhile starting point. Bearing in mind there may be agreements and disagreements, an independent facilitator might be helpful. In addition, some preliminary research to locate any relevant information could help inform the group on the scope of the problem, nationally or internationally. In brainstorming, some questions might be posed to guide the process:
   - What is the level of awareness in the community on the risks of alcohol use in pregnancy?
   - How many parents who are likely to become pregnant are consuming alcohol?
   - How many parents plan pregnancy?
   - How many individuals have a FASD diagnosis?

2. Once a decision is made in respect to prioritised activities, identify the target audiences (those who will directly and/or indirectly benefit most from the chosen activity). Some of the target groups are listed below.
   - Individuals (female and male) who are planning to become pregnant and who are users of alcohol or at increased risk of an unplanned pregnancy and who are users of alcohol
   - Those people who are able to support and ease the life demands on pregnant women – partners, family members, friends
   - Individuals recognised as at risk of FASD – children, adolescents and/or adults
   - Individuals with a diagnosis of FASD

3. Knowing how the outcomes will be reached and measured means identifying the opportunities within a community to attract the right audience and deciding on which messages need to be shared. The Prevention Conversation on Fetal Alcohol Spectrum Disorder offer suggested topics to consider in messaging.6

4. Engage with those with lived experience of the risk factors or the problem in creating messages and activities aimed at changing behaviour is critical. Find out what people know from life experience/s before choosing your key messages. This can be achieved by testing the key messages with the selected target groups. Choose short, simple messages that are easy to read

---

6 Prevention Conversation on Fetal Alcohol Spectrum Disorder https://preventionconversation.org/what-you-need-to-know/
and understand and avoid indicating that alcohol use is about ‘choice’ and that stopping drinking is ‘simple’. Use your key messages to link people to further information, services and support.  

5. Consider carefully which images/graphics you choose. Images are powerful and can have unexpected positive or negative impacts for pregnant women who use alcohol and for families affected by FASD. Unborn babies floating in alcohol beverage containers, babies drinking from a bottle containing alcohol or pregnant women drinking at a bar will probably attract attention but can be easily dismissed by many as a statement of “well that’s not me.” Again, test these with the selected target group in the planning stage.

**Caution: Some images are not culturally sensitive and may offend – a photo of a naked pregnant woman.**

6. Be aware of different patterns of alcohol use. As Shakeshaft advises:

   *There is a strong need to drink so that drinking is given priority over other behaviours that they had previously found much more important. This will include people whose dependence on alcohol may range from mild to severe. People with severe dependence drink regularly at high-risk levels, often find it hard to limit how much they drink, and generally have marked tolerance to the effects of alcohol.*

7. Build community support in the planning stage and continue “to foster and maintain community relationships.” Some individuals and/or groups worth considering are:

   - Aboriginal communities
   - Doctors – health care professionals – nurses, midwives
   - School communities - teachers/principals/counsellors etc
   - Alcohol and other drug services
   - People who work with children under school age
   - Juvenile Justice & corrective services
   - Mental health teams
   - Community groups eg men’s groups, elder’s groups
   - Community groups - Active Minds, church
   - Adults living with FASD
   - Allied health professionals – OT, speech, psychology etc
   - Bosses/workplace supervisors
   - Employment agencies
   - Family and Child Services
   - Parents and family members
   - Managers of playgroups, refuges
   - Police
   - Centrelink
   - Community leaders
   - Funding link
   - Social workers
   - Chambers of commerce
   - Alcohol industry representatives
   - Liquor Accords

---

---

---

---
8. Questions like ‘how will we know if we are successful’ or ‘what are the risks at each stage project’ can be considered in the planning stage. What could have been done differently is a question which can be answered after an event. These kinds of questions are important to continued learning and sharing. Bowen et al (2004) suggest asking:

- Are we doing the right things?
- Why are we doing things in a particular way?
- Are we doing things the right way?
- How does our activity relate to other alcohol prevention programs in our community? Can we tap in to these initiatives?
- Has the original objective behind our activity/activities changed since we began?
- Does our approach continue to be responsive to the needs of the initial target group?
- How do these activities affect outcomes for participants?

9. Who has what skills in your group – organizing, public speaking, negotiation etc. and match people with particular roles. Sometimes overlooked is the importance of documenting the process to enable tracking of planning, delivering activities and recorded outcomes. This is the narrative/story and vital to reporting and for media releases.

10. Connect with any other international or national projects to learn more about the experience. Breaking the Cycle (BTC) for example, is described as “an early identification and prevention program designed to reduce risk and to enhance the development for substance-exposed children (prenatal - 6 years) by providing services which address maternal addiction problems and the mother-child relationship through a community based cross-systemic model.” 12 Ideas and strategies can be drawn from projects like Sheway, a Canadian program that “provides health and social service supports to pregnant women and women with infants under eighteen months who are dealing with drug and alcohol issues. The focus of the program is to help the women have healthy pregnancies and positive early parenting experiences.”

14 Sheway http://sheway.vcn.bc.ca/
Four levels of prevention

In the following chart, four levels of prevention are listed under the headings of ‘upstream’ and ‘downstream’15.

<table>
<thead>
<tr>
<th>UPSTREAM</th>
<th>DOWNSTREAM</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Raise awareness, broad strategies target the whole community</td>
<td>3. During pregnancy, those who experience difficulty with abstinence are supported by safe services</td>
</tr>
<tr>
<td>2. Safe conversations targeted at groups considered at higher risk for an alcohol exposed pregnancy</td>
<td>4. Parents are supported to maintain or improve healthy choices</td>
</tr>
<tr>
<td>1.1 Media campaigns raise awareness, indicate where help may be needed, promote community involvement</td>
<td>Children have access to early diagnosis and early intervention</td>
</tr>
<tr>
<td>2.1 Screening and motivational interviewing &amp; education for any prospective parent who uses alcohol.</td>
<td>3.1 Key worker program for child and family</td>
</tr>
<tr>
<td>1.2 Participation in national and local calendar events</td>
<td>4.1 Intensive community and parenting support</td>
</tr>
<tr>
<td>2.2 The harmful use of alcohol across the lifespan and the times when young people should not use alcohol.</td>
<td></td>
</tr>
<tr>
<td>1.3 Peer led education - secondary and post-secondary schools/institutions</td>
<td>3.2 Educator training and support</td>
</tr>
<tr>
<td>2.3 Peer education program developed by students for other students</td>
<td></td>
</tr>
<tr>
<td>1.4 Information sessions/forums for service providers and community</td>
<td></td>
</tr>
<tr>
<td>2.4 Pregnancy planning</td>
<td>3.3 Self-advocacy kit</td>
</tr>
<tr>
<td>1.5 Resource distribution – postal, online</td>
<td>3.4 Case studies - clinical network meetings</td>
</tr>
<tr>
<td>2.5 Education for those who support girls and women at higher risk</td>
<td></td>
</tr>
</tbody>
</table>

Level 1 targets the whole community and not just girls and women who use alcohol. Every person can carry a prevention message.

Level 2 prevention targets groups at higher risk for alcohol use and unplanned pregnancies. More than half of the 250,000 pregnancies each year in Australia are reported to be unplanned and therefore pregnant women may be drinking before the pregnancy is confirmed. Anecdotal information suggests most women cease alcohol use upon confirmation of pregnancy. In a report by the Foundation for Alcohol Research and Education16 (FARE), slightly more than half of pregnant women reported not drinking at any stage during pregnancy. Of those who consumed alcohol prior to confirmation of the pregnancy, (47.3% of women surveyed), 19.5% reported continuing to consume alcohol. For others, alcohol use is problematic and may even be a dependence.

For this group, Level 3 comes into play and more intensive and supportive prevention is required to help people to stop drinking or at least to reduce their alcohol intake. Level 3 is sometimes called early intervention. A child at risk for FASD is now also considered. Early diagnosis and management are protective against secondary conditions developing over time.

Level 4 acknowledges that post-partum (after a baby is born), parents are supported to maintain or improve on the changes made during pregnancy and that any subsequent pregnancies are alcohol risk free.
Key messages

Key messages are necessary to provide accuracy and consistency. Nor are messages intended to shame or blame women. Research by France (2011) provides an insight to the use of fear-based messages about the risk of alcohol use in pregnancy. The research showed that such messages are effective for target groups of women who can achieve abstinence during pregnancy but are not helpful for women who need support to not use alcohol in pregnancy. Campaign design must consider questions which emerge from those parents who continue light drinking and acknowledge uncertainty about the risk to the fetus. Rather, the message needs to be an honest acknowledgement that the risk is real however no-one knows which fetus is vulnerable to the effects of alcohol exposure and that this is the central issue. As France notes, an “honest and scientific framing of the message and delivery by an expert source were also shown to minimize counterargument and strengthen the message’s persuasiveness” (p. 8).

* FASD prevention is not simply about a harm minimisation approach often applied to other alcohol and other drugs misuse. It goes one step further advocating that no alcohol equals no risk.
* For some, the outcome of fetal alcohol exposure can be severe whilst for others, there may be a very mild impact. Some may say they used alcohol in pregnancy and that their child is not affected. An outcome of FASD depends on the amount of alcohol, the pattern of drinking (binge or social), the stage of fetal development and/or intergenerational alcohol use. The really important message is that no one knows which pregnancy or fetus is at risk from prenatal alcohol exposure so no alcohol equals no risk.
* Not all difficulties experienced in life are attributable to alcohol use in pregnancy. However, some people may not even consider a possible connection between a very mild learning or other problem their child is experiencing with alcohol use in pregnancy. The really important message is that given the high numbers of pregnancies exposed to some amount of alcohol, even before pregnancy is confirmed means prenatal alcohol exposure should be included as a possibility.
* FASD lasts a lifetime however, with appropriate support and understanding, a good quality of life is achievable.
* Scientific evidence is building on the father’s use of alcohol as a factor influencing fetal alcohol risk.
* Changing attitudes and behaviours towards drinking when a pregnant woman is in social company is something that is very possible. If a pregnant woman is present for a celebration, a lunch or dinner engagement, make sure she enjoys this time. Family and friends should be encouraged to respect and support her choice to be alcohol free, join with her instead and not just assume pregnancy as a time she can be the designated driver.
* Use the current NHMRC Guidelines for reference:

  For women who are pregnant or planning a pregnancy, the safest option is not to drink alcohol. http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/guide-pregnant

  If you are breastfeeding, the safest option is not to drink alcohol. http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/guide-breastbr

Highlight - Narrabri NSW - A FASD Strategy in Development

In mid-2015, a CDAT organised a community forum on alcohol and other drug issues. Two presenters addressed FASD to over 50 participants. This well-received event was followed by an invitation to a FASD educator and trainer to visit the community for International FASD Awareness Day (September 9th) to deliver a one-day training workshop, an introductory session and to facilitate an initial meeting to collect data from which to develop the first stage in a FASD Community Action Plan.

The work of the CDAT representatives was to circulate throughout regional networks for expressions of interest in attending and the group was advised of the importance of an information session preceding the meeting. Over 30 people participated on the day representing government and non-government health and social services.

A description of FASD, factors influencing the use of alcohol in pregnancy, the diagnosis and management strategies were covered in the information session in the morning.

In the afternoon, a prevention grid was used to begin the process of generating and collecting ideas from participants on community need and possible strategies. This process began to answer the question ‘what could we do?’

<table>
<thead>
<tr>
<th>Level of Prevention</th>
<th>Alcohol &amp; Pregnancy (pre-birth)</th>
<th>Living with FASD (post birth)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raise community awareness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Target those at higher risk</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provide early Intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Offer postpartum support</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The next step was to organise the data into emerging themes. Sub headings were selected - campaigns/community education and partnerships – to begin to answer ‘if and how’ these ideas might be achieved. Some types of initiatives are included in Table 2 (see p.16) and examples are listed in Table 3 (see p. 18).

The Narrabri CDAT has reached this point. In the future, circulating the data to the original participants with the aim of consensus is an important next step. It is respectful and helps to sustain participation and interest. Proposing a time frame for feedback to be received is a good management strategy. This is also an opportunity to invite interested participants to join a core management group.
Once formed, the group should meet to begin planning in earnest focused on some key questions:

1. From the consultation data, what is the priority?
2. What activities will we select and how will we achieve these activities?
3. Who is not in the room but important to the group objective/s?
4. What is the time frame? Is this practical for arranging, organising and delivery?
5. What resources do we have at hand (physical, human, financial, time)?
6. Who will do what (organise, media, resource development etc)?
7. What are the ‘gaps’?
8. How we will know if what we choose to do is effective? How will we measure it?
9. How do we know we’ve achieved what we aimed to do?”
10. Are we prepared to report the experience, whether a part of the experience works or not?
11. How will we report on the outcomes – to whom and for what purpose?
Newcastle FASD Strategy

The Newcastle CDAT first convened a forum in December 2014 which was attended by 50 locally based organisation representatives and other interested individuals. There was consensus to develop, implement and evaluate a local FASD Strategy with “a proportionate coordinated response to address this problem required from all local stakeholders and all levels of government to integrate three streams: (i) prevention and education; (ii) screening, diagnosis and treatment and, (iii) life-long community support for those diagnosed and their parents and carers.”

Acknowledging the prevalence of FASD as underascertained, the discussion paper which followed included data on the rate of risky drinking in Hunter New England among women had increased 1.4 per cent, from 22.6 per cent in 2002 to 24 per cent. It was claimed that this is the second highest rate of female risky drinking in NSW. The discussion paper also reflected on the 50% of unplanned pregnancies and the risk of alcohol consumption prior to confirmation of pregnancy, that patterns of alcohol use are often a social based phenomenon.

A multi-agency/community working group chaired by the Newcastle CDAT formed and convened to progress the holistic development of the strategy – key elements of which were determined during the meeting and identified the Strategy be framed on inclusiveness, an evidence based approach, consistency with national and state strategies, and operate with dignity, sensitivity and respect.

Patterns of drinking are understood to include social patterns of alcohol use; FASD is not regarded as just an issue for women/mothers or the Aboriginal community. FASD prevention also takes into account the important role of partners, family members and friends.

Awareness of health care providers and other professionals interfacing with women at risk of FASD and children who may be living with FASD was agreed to be quite low and extended across the broad spectrum of schools, social services, child care and health including GPs.

The work to date has been a result of volunteer input and a future funding commitment didn’t materialise which has slowed down progress.

---

18 Information from the Newcastle FASD Strategic Plan development process was kindly shared in interview with Tony Brown (2016)
## Levels of Prevention and Types of Initiatives

<table>
<thead>
<tr>
<th>Level of Prevention</th>
<th>Alcohol &amp; Pregnancy (pre-birth)</th>
<th>Living with FASD (post birth)</th>
</tr>
</thead>
</table>
| Raising community awareness | **Campaigns/Community Education**  
Posters in public bathrooms, licenced premises, under aged friendly venues, PCYC, emergency departments, doctor’s surgeries, public transport and community centres.  
Media campaigns eg local radio, TV.  
Alternative non-alcoholic drinking choices.  
Information packs for parents with children starting school.  
Promoting conversations via fact sheet and tool box meetings in workplaces including where men work. Schooner and wine classes with FASD etched into as logo with info on beer mats, stickers on cases of beer.  
Promotion of prevention messages in secondary schools through current sex education and alcohol and other drug use presentations.  
Education sessions with teachers/child health and other health professionals.  
GP education/awareness ‘ask about drinking in pregnancy’ | Health promotion signs at parks, pool, places women take children  
Info in packs available to new parents at hospital prior to discharge. |
| Building community capacity through partnerships | **Local government, liquor accord, CDAT, police- crime prevention committee, perinatal working group, education, women’s refuge.**  
Interagency collective response on 9 Sept @ 9h 9min  
Promote agendas – change laws eg serving alcohol to pregnant women, alcohol restrictions in communities, clear guidelines that state NO alcohol is safe when pregnant, FASD government funded service.  
Midwifery Services – mother’s groups, class education, yoga in pregnancy, awareness to both parents/couple, | Young mums/antenatal program.  
Safe Start meetings which flags ‘at risk’ mothers  
Antenatal education – clinics/checks, provide information.  
Connected Community |
| Target those at higher risk | **Building community capacity through partnerships**  
Local government, liquor accord, CDAT, police- crime prevention committee, perinatal working group, education, women’s refuge. | Promote agendas:  
Universal screening yrs 5 & 6 added into full health assessments.  
Contraception education and options. |
| Early Intervention | Building community capacity through partnerships | Local government, CDAT, police- crime prevention committee, perinatal working group, education, women’s refuge. Promote conversations:  
- New Australian diagnostic implement  
- Screening tools for different professions.  
- Increasing direct contact support for parents and families.  
- Diagnosis of parent with FASD  
- Intergenerational alcohol exposure/use  
- Referrals protocols  
- Social determinants of health  
- Regular medical check-ups & follow ups | Promote development of formal protocols:  
- Adapted screening tools for different professions. Increase direct contact support for parents and families.  
- Safe Start meetings – ‘at risk’ mother’s previous history of AOD  
- Gathering family history  
- Diagnosis of either parent with FASD  
- Intergenerational alcohol exposure/use  
- Referrals to appropriate family services  
- Supporting people living with FASD to shine and show strengths – sport/music etc.  
- Promote inclusion and acceptance of child/adult |
|---|---|---|
| Postpartum support | Building community capacity through partnerships | Perinatal working group, education, women’s refuge. | Treatment options for parents  
Increase direct contact and/or mentor support for parents and families. |
### Examples of Current FASD Prevention Initiatives

<table>
<thead>
<tr>
<th>Description</th>
<th>Who is doing it?</th>
<th>How effective is it?</th>
<th>Improvements? How?</th>
<th>What resources exist?</th>
<th>What resources could ADF develop?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>International FASD Awareness Day</strong> – focus is on 9.09 am on the 9th day of the 9th month. Begins in NZ, crosses Australia to South Africa and Europe ending in Toronto, Canada as the world turns through different time zones.</td>
<td>International</td>
<td>Probably works based on the overall concept which has endured for almost two decades (global event since 1999). Non-gendered and age and culturally diverse activity. Flexibility in selecting activities, adaptable to a range of settings. Ideas include BreakFASD, Braided Cord or Knot, Pregnant Pause as listed below.</td>
<td>Register with NOFAS in the USA or EUFASD in Europe, skype to join with other communities.</td>
<td>Download from a range of sources <a href="http://www.fasday.com">http://www.fasday.com</a> <a href="http://nofasd.org.au">http://nofasd.org.au</a> <a href="http://nofas.org">http://nofas.org</a> Lighter Side of FASD: 60 activities you can access in the lead up to International FASD Awareness Day 2016 <a href="http://jodeekulp.blogspot.com.au/p/fasday-60-days-of-ideas.html">http://jodeekulp.blogspot.com.au/p/fasday-60-days-of-ideas.html</a></td>
<td>Support roll out and connect up by Skype across events</td>
</tr>
<tr>
<td><strong>BreakFASD</strong> A planned start at about 8.00am is necessary so that invited guests can have coffee and breakfast (muffins, pastries) before the guest speaker presents on a relevant FASD topic. Often used to mark 9.09am for International FASD Awareness Day.</td>
<td>International</td>
<td>Probably works to raise awareness. Non-gendered and age and culturally diverse activity. Flexibility in selecting activities.</td>
<td>The inclusion of those who are outside the group ‘who usually turn up.’ More likely to attract service providers as the event is concluded by 9.00am. Food is a drawcard. Include a ‘freeze frame’ and invite dignitaries to attend and participate. This is of interest to media and for a photo shot.</td>
<td>Internet search will reveal multiple sites.</td>
<td>Identify key presenters. Attend event.</td>
</tr>
<tr>
<td>Description</td>
<td>Who is doing it?</td>
<td>How effective is it?</td>
<td>Improvements? How?</td>
<td>What resources exist?</td>
<td>What resources could ADF develop?</td>
</tr>
<tr>
<td>-------------</td>
<td>-----------------</td>
<td>----------------------</td>
<td>---------------------</td>
<td>----------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td><strong>Braided Cord or the FAS Knot</strong></td>
<td>USA/Canada</td>
<td>Probably works for raising awareness and offers an opportunity to engage community. Adaptable (settings and contexts). Cord can be created as a badge for a key message.</td>
<td>A simple activity that anyone can join in.</td>
<td>Online instructions <a href="http://www.come-over.to/FASDAY/manual.htm">http://www.come-over.to/FASDAY/manual.htm</a></td>
<td>Connect with craft groups to put together an instruction kit and supplies. Badges could be produced to acknowledge project.</td>
</tr>
<tr>
<td><strong>Ask Me About FASD—a sticker on mirrors or a badge to wear. A script and information is provided to all the hairdressers in a community.</strong></td>
<td>Based on an anecdotal description from the Lakeland FASD Clinic, Alberta Canada</td>
<td>Probably works for raising awareness. Based on assumption that many people use hairdressers.</td>
<td>Adaptable to different work spaces that have strong public access. May focus on a work site/s for example, local industry or all government offices. May also focus on school communities. Possibility high for female targets depending on choice of site for activity.</td>
<td>What men can do to support partners[^19] Also see components of FASD prevention from a women’s health determinants perspective[^20]</td>
<td>Stickers. Printed fact or information sheets. Replicate poster or info sheet – “Alcohol, Pregnancy and Prevention of Fetal Alcohol Spectrum Disorder: What men can do to help.”[^15]</td>
</tr>
</tbody>
</table>

[^19]: [Canadas FASD Research Network’s Action Team on FASD Prevention from a Women’s Health Determinants Perspective](http://bccewh.bc.ca/wp-content/uploads/2014/05/what-men-can-do_-_final-feb-2014.pdf)

<table>
<thead>
<tr>
<th>Description</th>
<th>Who is doing it?</th>
<th>How effective is it?</th>
<th>Improvements? How?</th>
<th>What resources exist?</th>
<th>What resources could ADF develop?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take the Pledge</td>
<td>NOFASD Australia</td>
<td>Probably works, good non-gender specific activity. Sign up to not consume alcohol on International FASD Awareness Day. Share with others via social media.</td>
<td>Something that could be done through the ADF website/social media networks/local radio.</td>
<td>NOFASD Australia – social media. Example: <a href="http://www.internationalwomensday.com">http://www.internationalwomensday.com</a></td>
<td>Partner with other organisation or workplace to attract male parents/partners</td>
</tr>
<tr>
<td>Alcohol. Think Again Campaign</td>
<td>Drug and Alcohol WA &amp; the Injury Control Council WA</td>
<td>Works. Evaluation available on website. This campaign aimed to decrease alcohol-related harm by changing the drinking culture in Western Australia to support safer drinking environments and practices. The campaign has had different stages and different focuses one of which might provide some ideas about application in other communities.</td>
<td>Develop a similar campaign.</td>
<td>Example of an advertisement and description[21]</td>
<td>Partner with Alcohol and Other Drug Services or peak organisations like NADA to develop a similar campaign.</td>
</tr>
<tr>
<td>The Strong Spirit-Strong Future Campaign</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women Want to Know</td>
<td>FARE, Australia</td>
<td>Probably works. Evaluation in progress.</td>
<td>Safe relational based environments to disclose and this might not be in a health service environment for all women. It is an example of why the engagement of the intended target group is so critically important from the outset and throughout the project.</td>
<td>Women Want to Know[23]</td>
<td>Reference to NHMRC Alcohol Guidelines, use of screening tools, motivational interviewing, diagnostic instrument links on ADF website.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Description</th>
<th>Who is doing it?</th>
<th>How effective is it?</th>
<th>Improvements? How?</th>
<th>What resources exist?</th>
<th>What resources could ADF develop?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lilliwan Project</strong>&lt;sup&gt;24 25&lt;/sup&gt;, Fitzroy Valley, WA</td>
<td>Collaborative</td>
<td>Works. Whole of community project with cultural sensitivity paramount. Reduction in alcohol use in pregnancy is reported. Results not yet published.</td>
<td>In progress.</td>
<td>The Marulu Strategy&lt;sup&gt;26&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>A community initiative to overcome Fetal Alcohol Spectrum Disorders (FASD) and Early Life Trauma (ELT)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Bring FASD Awareness to Rural and Remote Areas</strong></td>
<td>Lightening Ridge CDAT</td>
<td>New project yet to be launched. Probably works for raising awareness and good strategy for promoting ongoing and safe conversation It is gender specific however is offered in alternative settings. The program will be sustained by follow up consultations and evaluations in the communities of the Walgett Shire, by education and the building of supporting networks, as well as working towards inclusion of partner and family support for the identified target group Evaluations, participant lists and feedback to be recorded at each event.</td>
<td>Pre and post evaluation probably helpful in measuring longer term outcomes. Use of FASD manikins limits understanding of FASD occurring on one part of the fetal alcohol spectrum. This is the old diagnosis of Fetal Alcohol Syndrome – facial features, small growth and should be accompanied by clarification of severe to subtle impact.</td>
<td>New project. Resources available through myriad of websites.</td>
<td>A script for women and young girls to share with their individual networks.</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Description</th>
<th>Who is doing it?</th>
<th>How effective is it?</th>
<th>Improvements? How?</th>
<th>What resources exist?</th>
<th>What resources could ADF develop?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Start a support group</td>
<td>Russell Family Fetal Alcohol Disorders Assoc. (rffada)</td>
<td>Works for sharing parenting experiences. Online only except for Gold Coast.</td>
<td>Opportunities exist in regional centres to establish direct contact support groups. Allocate resources to ensure the process is guided and professionally supported. Terms of Reference particularly important to ensure confidentiality and assure privacy for children.</td>
<td>Contact details can be found on the rffada Australia website <a href="http://www.nofasd.org.au/">http://www.nofasd.org.au/</a> FASDAY website (USA) <a href="http://www.fasday.com/">http://www.fasday.com/</a> FASD Consultants Australia can help support group development. <a href="http://fasdconsultants.com.au/">http://fasdconsultants.com.au/</a></td>
<td></td>
</tr>
<tr>
<td>FASD Prevention videos</td>
<td>Alaska Mental Health Authority</td>
<td>Probably works for raising awareness. Highly regarded and selected video could be played in conjunction with a BreakFASD event or in educating community groups or in secondary schools.</td>
<td>No improvements noted. The fourth listed is particularly good.</td>
<td>Alaska Mental Health Authority[^27^] online videos. 1. FASD: Know the Basics 2. FASD: Myths 3. FASD: Why a diagnosis is important 4. FASD: Expanding Services – Why?</td>
<td>Particularly No. 4 should be replicated for wider Australian distribution.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Description</th>
<th>Who is doing it?</th>
<th>How effective is it?</th>
<th>Improvements? How?</th>
<th>What resources exist?</th>
<th>What resources could ADF develop?</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Story of Alcohol Use in Pregnancy and FASD</td>
<td>FARE</td>
<td>Good resource for use in raising professional awareness of FASD</td>
<td>Limited information on strategies for care.</td>
<td>DVD can be purchased through FARE(^{28})</td>
<td>Purchase copies for loan.</td>
</tr>
<tr>
<td>Multicultural - FASD</td>
<td>Multicultural CDAT (including the Hunter New England Local Health District and Catholic Care)</td>
<td>Probably works.</td>
<td>Early stages of development.</td>
<td>Limited.</td>
<td>Support this initiative as it is likely to be an Australian first.</td>
</tr>
<tr>
<td>Narrabri FASD Strategy</td>
<td>CDAT</td>
<td>Probably works. In development.</td>
<td>Focus on re-engagement with original interest groups.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Newcastle FASD Strategic Plan</td>
<td>CDAT</td>
<td>Probably works. In progress Slowed up by absence of health workers withdrawn from project and reliance on volunteers to drive the process.</td>
<td>Focus on one system to build momentum and interest. Financial support for salaries and on costs to complete the FASD Strategy, a template for other communities across NSW and Australia.</td>
<td>Draft document.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Description</th>
<th>Who is doing it?</th>
<th>How effective is it?</th>
<th>Improvements? How?</th>
<th>What resources exist?</th>
<th>What resources could ADF develop?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Beaches NSW</td>
<td>The Northern Beaches CDAT</td>
<td>Probably works. Consultation with the different cultural communities is positive. International students participating in survey. P-CAP example in resources list is a highly evaluated program.</td>
<td>Women need safe places for conversations so worth looking at where and with whom women meet to then engage these providers/supporters in the sharing of information. Also consider engaging with partners and families. Consider pregnant women who may be living with FASD themselves and user friendly information – words and pictures.</td>
<td>Rutman D (2011) 29 Infographics 30 CanFASD Northwest’s Network Action Team 2010 31 Parent-Child Assistance Program (P-CAP)</td>
<td>Information as fact sheets on ADF website.</td>
</tr>
</tbody>
</table>

