

### III. Prevention

<i>Learning Objectives and Activities</i>	
<ul style="list-style-type: none"><li>● <i>Identify strategies for prevention of FAS/ARND as a primary disability</i></li><li>● <i>Identify strategies for prevention of secondary disabilities associated with FAS/ARND</i></li><li>● <i>Discuss Streissguth's "5 P's of Prevention"</i></li><li>● <i>Identify tools and strategies which facilitate prevention efforts and referrals for diagnosis of FAS/ARND</i></li></ul>	
<i>Presenters and Materials</i>	
<ul style="list-style-type: none"><li>● <i>Curriculum, chapter III.</i></li><li>● <i>Identification of Local Prevention Efforts Worksheet</i></li><li>● <i>Screening Questions Worksheet</i></li></ul>	

#### **How Can FAS/ARND Be Prevented?**

The prevention of FAS/ARND requires two approaches: prevention of the primary disability and prevention of secondary disabilities associated with FAS. The prevention of primary and secondary disabilities requires a broad network of skills and support.

Primary prevention focuses on reducing the occurrence of FAS/ARND in the community. The goal in primary prevention is to ensure that no babies are born with FAS, thus abstinence from alcohol consumption during pregnancy is the key to prevention of the primary disability.<sup>23</sup> Raising education and awareness are the keys to this approach.

The prevention of secondary disabilities focuses on inhibiting the developmental delays and behavioral problems associated with the primary disability. Delays in diagnosis of FAS/ARND or intervention can trigger secondary disabilities such as mental health problems, inappropriate sexual behavior, school drop out, run-ins with the law and alcohol and substance abuse problems.

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23. <http://www.nursece.com/onlinecourses/9012.html>.

The primary disabilities associated with FAS/ARND range from mild to severe damage to the fetus' central nervous system (CNS) in utero, growth deficiency present at birth, abnormal head circumference indicating organic brain damage, and physical dysmorphia, or abnormality of shape. The primary disabilities are often accompanied by subsequent secondary disabilities including attention and memory deficit problems, depression, auditory and visual hallucinations, panic attacks and suicidal threats and attempts.<sup>24</sup> Various combinations of the primary and secondary disabilities will manifest in each child with FAS/ARND in different ways. Thus, parents/caretakers and teachers must be willing to try varying approaches in their parenting, teaching, and intervention strategies.

Prevention of the primary disability is often perceived as the burden of the individual mother, her inner circle of friends and family and to a great extent the community and whether it provides FAS/ARND awareness resources. Education and community outreach are key factors in determining whether or not a mother will eliminate alcohol from her diet before and during pregnancy. Community outreach tools such as brochures and pamphlets that explain the risks and potential harm of exposing a developing fetus to alcohol are commonly used to educate about FAS/ARND. Education about FAS/ARND should begin very early with information campaigns for children. Health care providers and education professionals should collaborate to provide broad-based education programs to young adults through academic curriculum.

Prevention of the secondary disabilities requires a concentrated effort by a broader network of parents, families, teachers, healthcare and other service providers who can develop protocols for screening school children for FAS/ARND, develop multi-disciplinary teams consisting of educators and service providers who have been cross-trained about FAS/ARND and intervention strategies, and promote public outreach programs that will provide information on

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24. Streissguth, A. and O'Malley, K., Fetal Alcohol Syndrome/Fetal Alcohol Effects: Secondary Disabilities and Mental Health Approaches, <http://depts.washington.edu/fadu/Tr.today.97.html>. (2/14/02).

diagnosis of FAS/ARND and the resources available to parents and teachers for responding to children with FAS/ARND.

Children with FAS/ARND cannot be treated in a vacuum. Each child and the extent of their secondary disabilities are different. Each must receive seamless services and resources directed at their particular secondary disabilities. Children with FAS/ARND are commonly diagnosed with one or more developmental disabilities or mental health problems.<sup>25</sup> Environmental stressors may aggravate a secondary disability or underlying problem. It is wiser to begin treatment by attempting to look at areas of stress in the environment than to plunge into the use of medications, such as stimulants, anti-depressants, and anti-psychotics.<sup>26</sup> Managing the various environmental stressors that a child with FAS/ARND may come into contact with is a task that requires honest and informed discussion between parents, teachers and others who provide care to the child.

Prevention programs directed at FAS/ARND require sensitivity to the uniqueness of the disability and the commonalities among those affected. To overlook the special needs of FAS/ARND children and to treat them for a different or secondary diagnosis will only cause further stresses to the child and their caretaker(s). In addition to the sensitivity and awareness of behavioral patterns associated with FAS/ARND, health care providers, caretakers and teachers must also maintain an awareness of the cultural background of the parent, caretaker or community. The cultural background may hinder or help prevention efforts, but if ignored, will certainly pose obstacles to the prevention and treatment efforts.

One way tribal communities can begin prevention efforts in their communities is by screening all women of childbearing age for at-risk drinking behavior. Once at-risk individuals are identified, then appropriate education and counseling can be utilized to deter drinking both

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25. Id.

26. Id.

before and after conception.<sup>27</sup> Thus identification and treatment of women of childbearing age at risk for alcohol abuse are critical to the prevention of FAS/ARND.<sup>28</sup> A routine system for screening women for alcohol problems should be incorporated into the daily routine of Indian Health Service staff, social service providers and tribal justice systems personnel who have been trained to administer screening questions for the purposes of referral for full screening or diagnosis. Screening can be done via a face-to-face interview or by a self-report questionnaire. Individuals administering questions should proceed in a nonjudgmental style and protect the confidentiality of the interviewee.<sup>29</sup> The screening should follow a four-step process: ask, assess, advise and follow up. Step one should involve asking the individual about their alcohol use. Interview questions should be directed at their frequency of use, their tolerance of alcohol, whether or not they engage in dependent or binge behaviors, and whether or not their family members show concern for their use.<sup>30</sup> Step two involves assessment for alcohol related problems. Special attention should be given to those individuals who exhibit use of seven or more drinks per week and/or three or more drinks per occasion. Assessment questions should be directed toward medical issues, behavioral issues, withdrawal and/or depression, employment problems, alcohol related accidents, trouble with the law and family concern for behavior. During step three of the process the screener/interviewer should advise the individual on appropriate action. Health problems associated with alcohol use should be discussed. Risks during pregnancy should be discussed in addition to characteristics and consequences of having a child with FAS/ARND. The screener/interviewer should work with the individual to establish goals to reduce drinking and refer her to specialized treatment if needed.<sup>31</sup> If the individual is preg-

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27. Identification of At-Risk and Intervention with Women of Childbearing Age, NIH Publication No. 99-4368, 1999, p. 6.

28. Id at 11.

29. Id at 13.

30. Id at 12.

nant, is planning to become pregnant, or is having unprotected sexual intercourse, she should always be advised to abstain from the use of alcohol. Step four requires following up on the individual's progress. The screener/interviewer or their representative can assist the individual with access to treatment, medical care or offer additional resources.<sup>32</sup> Screeners/interviewers should look out for other indicators of alcohol use. Screener/interviewers should anticipate a fair share of dishonest or inaccurate responses. Individuals who are alcohol and drug dependent, long time users or who actively and regularly use large quantities, and/or persons with psychiatric disorders fear the consequences of reporting their behavior.<sup>33</sup> Individuals who abuse and are pregnant or have other children will be especially fearful of having their child/children removed. Thus it is important that the screener/interviewer use the utmost sensitivity throughout the process. Other indicators of at-risk alcohol use may be a history of adverse pregnancy outcomes, high-risk sexual behavior, accidents and injuries, depression, domestic violence, child abuse, family problems, and employment issues. Associated health problems are liver disease, heart disease, cancer, and osteoporosis.<sup>34</sup>

There are a number of screening instruments available to assist with detection and use

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31. Id.

32. Id.

33. Id at 13.

34. Identification and Care of Fetal Alcohol exposed Children, NIH Publication No. 99-4369, 1999, p. 3.

assessment. See chart below for current screening instruments.

Information about administering T-ACE is available at [www2.health-center.com/mentalhealth/](http://www2.health-center.com/mentalhealth/)

### **Alcohol Use Screening Instruments<sup>35</sup>**

<b>The following four (4) screening instruments are most commonly used to screen for alcohol use among pregnant women. In addition, the T-ACE questions were specifically evaluated for use among Native American pregnant women in a self-administered questionnaire format (see Bad Heart Bull, Kvigne, Leonardson, Lacina and Welty, AM J Prev Med 1999; 16(3) for further information).</b>	
<b>AUDIT</b>	(Alcohol Use Disorders Identification Test) 10 questions which aim to detect hazardous drinking. This test is most effective in detecting at risk, hazardous or harmful drink-
<b>CAGE</b>	(Cut down Annoyed Guilty Eye-opener) 4 questions that aim to detect alcohol abuse and dependence. This test is superior at detecting alcohol abuse or dependence.
<b>T-ACE</b>	(Tolerance Annoyed Cut down Eye-opener). This test is more sensitive and specific for screening pregnant women.
<b>TWEAK</b>	(Tolerance Worried Eye-opener Amnesia K(C)ut down) screens for alcohol problems in pregnant women.
<b>Additional screening instruments, which are not specifically designed for pregnant women include:</b>	
<b>SADD</b>	(Short Alcohol Dependence Data Questionnaire) 15 item self completion assessment of dependence severity.
<b>S-MAST</b>	(Short Michigan Alcoholism Screening Test (also B-MAST)) 13 item self completion assessment instrument.
<b>Trauma Scale</b>	5 questions on alcohol related trauma.

[alcoholinfo/physicianalcoh/alcohol\\_screen/tace.htm](http://alcoholinfo/physicianalcoh/alcohol_screen/tace.htm). Information about administering

TWEAK is available at [www.niaaa.nih.gov/publications/tweak.htm](http://www.niaaa.nih.gov/publications/tweak.htm). Samples of the instruments are contained on the following pages.

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35. For more information, see Alcohol-Screening Instruments for Pregnant Women, by Dr. Grace Chang, <http://www.niaaa.nih.gov/publications/arh25-3/204-209.htm>.

**Brief Screening Test: TWEAK<sup>36</sup>**

**Read It On Charlotte Kasl's Women At Risk Website  
Charlotte Kasl, *Many Roads, One Journey: Moving Beyond the 12 Steps.*  
Charlotte Kasl, P.O. Box 1302, Lolo MT 59847**

*Do you drink alcoholic beverages? If you do, please take our "TWEAK Test."*

<b>T</b>	<p><b>Tolerance:</b> How many drinks does it take to make you feel high? (Record number of drinks)</p> <p>_____</p> <p><i>Score 2 points if she reports 3 or more drinks to feel the effects of alcohol. Score: _____</i></p>	<b>No. of drinks</b>
<b>W</b>	<p><b>Worry:</b> Have close friends or relatives worried or complained about your drinking in the past year?</p> <p>_____ Yes _____ No</p> <p><i>Score 2 points for a positive "yes". Score: _____</i></p>	
<b>E</b>	<p><b>Eye-Opener:</b> Do you sometimes have a drink in the morning when you first get up?</p> <p>_____ Yes _____ No</p> <p><i>Score 1 point for a positive "yes". Score: _____</i></p>	
<b>A</b>	<p><b>Amnesia (Blackouts):</b> Has a friend or family member ever told you about things you said or did while you were drinking that you could not remember?</p> <p>_____ Yes _____ No</p> <p><i>Score 1 point for a positive "yes". Score: _____</i></p>	
<b>K(C)</b>	<p><b>Cut Down:</b> Do you sometimes feel the need to cut down on your drinking?</p> <p>_____ Yes _____ No</p> <p><i>Score 1 point for a positive "yes". Score: _____</i></p>	

*Total Score = \_\_\_\_\_*

*A total score of 2 or more points indicates a likely drinking problem.*

Source: Russel, Marcia, Martier, Susan S., Sokol, Rober J., Mudar, Pamela, Bottoms, Sidney, Jacobsen, Sandra & Jacobsen, Joseph (1994). Screening for Pregnancy Risk-Drinking. *Alcoholism: Clinical and Experimental Research*, 18 (5): 1156-1161.

36. <http://www.niaaa.nih.gov/publications/tweak.htm>.

## Brief Screening Test: T-ACE

Read It On Charlotte Kasl's Women At Risk Website  
Charlotte Kasl, *Many Roads, One Journey: Moving Beyond the 12 Steps*.  
Charlotte Kasl, P.O. Box 1302, Lolo MT 59847

T-ACE is a measurement tool of four questions that are significant identifiers of risk drinking (i.e., alcohol intake sufficient to potentially damage the embryo/fetus).

The T-ACE is completed at intake. The T-ACE score has a range of 0-5. The value of each answer to the four questions is totaled to determine the final T-ACE score.

**Note:**

- 1 Drink  
= 12 oz beer  
= 12 oz cooler  
= 5 oz wine  
= 1 mixed drink (1.5 oz. hard liquor)

Binge (drinking) = consuming 4 or more alcoholic drinks on an occasion

**A total score of 2 or greater indicates potential risk for the purposes of Pregnancy Outreach Program identification of prenatal risk.**

1. How many drinks does it take to make you feel high? 1. less than or equal to 2 drinks 2. more than 2 drinks	<b><u>Tolerance</u></b>
2. Have people annoyed you by criticizing your drinking? 1. No 2. Yes	<b><u>Annoyance</u></b>
3. Have you felt you ought to cut down on your drinking? 1. No 2. Yes	<b><u>Cut Down</u></b>
4. Have you ever had a drink first thing in the morning to steady your nerves or to get rid of a hangover? 1. No 2. Yes	<b><u>Eye Opener</u></b>

**Total Score = \_\_\_\_\_**

Source: Sokol, Robert J., "Finding the Risk Drinker in Your Clinical Practice" in G. Robinson and R. Armstrong (eds), *Alcohol and Child/Family Health: Proceedings of a Conference with Particular Reference to the Prevention of Alcohol-Related Birth Defects*. Vancouver, BC., December, 1988.

## **Five P's of Prevention**

Fetal Alcohol Syndrome is a completely preventable condition: if a woman does not drink alcohol during pregnancy, her child will not suffer from FAS/ARND. Due to the prevalent use and abuse of alcohol in the United States, prevention of FAS disorders must be approached from two directions: (1) prevention of FAS/ARND by educating women of child bearing age and their potential mates that alcohol consumption during pregnancy (conception to birth) may result in FAS disorders; and (2) prevention of secondary disabilities associated with FAS/ARND by educating persons with FAS, their families and their communities about providing programs and environments that allow for support and tools to manage the behaviors characteristic of the secondary disabilities.

A. Prevention of FAS by educating women of child bearing age and their potential mates that alcohol consumption during pregnancy (conception to birth) may result in FAS disorders.

In "Fetal Alcohol Syndrome: A Guide for Families and Communities," Ann Streissguth, Ph.D., has developed the "Five P's of Prevention" as follows:

1. Public Education is focused on educating the public at large about the dangers of drinking during and before pregnancy. She suggests public education using a variety of formats including posters, lectures, brochures and media attention.
2. Professional Training is focused on teaching healthcare and social service professionals about FAS and how to discuss FAS with their patients.
3. Public Policy refers to rules, laws and policies developed by government or its agencies to respond to consumption of alcohol when pregnant. The Public Policy form of prevention can be a very powerful tool in tribal

communities for the prevention of secondary disabilities, as well.

4. Programs and Services include governmental and non-governmental programs and services that intervene with or support women who become pregnant or who have given birth.
5. Parent and Citizen Activism is a form of prevention in which the community social standards are reevaluated and asserted to discourage women from consuming alcohol when pregnant.

Collectively, the “Five P’s of Prevention” focus all major community tools (government, the citizens, educational forums) on the task of disseminating information and taking actions that will support women who become pregnant and discourage consumption of alcohol when pregnant.

- B. Prevention of secondary disabilities associated with FAS by educating persons with FAS, their families and their communities

The prevention of secondary disabilities associated with FAS should be approached with the same effort as outlined in the “Five P’s of Prevention” with the focus on managing the behaviors characteristic of the secondary disabilities which manifest in the child or adult with FAS. Since the characteristics vary from developmental stage to developmental stage, this task requires a great deal of education for all persons (family, teachers, governmental personnel) and planning by governmental and non-governmental agencies to assist in providing a safe, structured environment in which the child or adult with FAS may thrive. The purpose of this curriculum is to provide such information for tribal justice system personnel (i.e., council members, judges, law enforcement, probation officers). The following are some suggestions for preventative actions that a community can take to minimize the negative impacts of secondary disabili-

ties associated with FAS.

1. Respite Programs should be provided for caretakers and teachers of FAS students allowing for periodic breaks from care taking and teaching duties in order to delay or prevent stress and burnout. A respite program does not have to be purely for daycare purposes. An excellent example of a respite program is “*The Aunties Program*” (Lummi Reservation/ Seattle, WA) which provides in-home visits with a service provider who assists the new parent(s) in applying parenting, child care and home care skills.
2. Professional Training should be provided to governmental and non-governmental personnel who may have the earliest or most frequent contact with a child with FAS to provide a better network for identification and referral for diagnosis. For example, parents and teachers are apt to spend the most time with children; however, without comprehensive training about FAS they may not identify early symptoms of secondary disabilities. Another example of a key group within the tribal community will be grandparents and extended family members who may provide care or spend more time with a child with FAS than the parent or the teacher.
3. Accessible Programs and Services should be identified and publicized. If no local programs currently exist, then consistent local public awareness programs should be held that (1) identify nearest accessible resources for the community and (2) discuss the process and consequences of obtain-

ing a diagnosis of FAS or ARND.

4. Policies and Procedures should be adopted by governmental agencies which facilitate interviewing of expectant mothers concerning alcohol consumption and screening of children to determine if referral for FAS/ARND diagnosis is appropriate by social services, medical and probation personnel; protect families and maintain confidentiality regarding diagnosis of FAS/ARND.
5. Public Education about the importance of early identification and screening of children that may be affected by FAS/ARND.
6. Multidisciplinary Teams should be used to develop approaches in developing governmental policies and individual treatment plans for persons with FAS/ARND. The law and policy makers must tap into justice, medical and social welfare personnel to determine the cost-benefit analysis for allocating resources towards early identification, screening and diagnosis of FAS/ARND. The burden upon the juvenile justice system, especially the probation services, should be used as an evaluation standard when new policies are adopted and evaluated.

An example of an FAS/ARND awareness and education brochure is contained on the following pages.

## You Can Take Action!

- Stop drinking now if you are pregnant or nursing.
- Stop drinking now if you are planning to become pregnant or there is a possibility you might be pregnant.
- If you know someone who is pregnant and drinking alcohol, encourage her to stop.

## Cutting down on alcohol use is not enough.

Even moderate alcohol use during pregnancy can cause your unborn child a lifetime of physical and mental problems.

## Find Support!

- *Friends/Family*
- *Community*
- *Indian Health Service Hospitals and Clinics*
- *Health Representatives and Wellness Workers*
- *Safe homes and shelters*
- *Native or Culturally Relevant Alcohol and Drug Rehabilitation Programs*
- *Teachers*
- *Elders*
- *Spiritual or Religious Leaders*

# Choosing a Path of Prevention

**Against Fetal Alcohol Syndrome and Alcohol-Related Neurodevelopmental Disorders**



For more information about Alcohol Abuse please contact your local Indian Health Services Provider:  
Phone:

For more information about Fetal Alcohol Syndrome and alcohol-related disorders contact:

The Centers for Disease Control and Prevention  
National Center on Birth Defects and Developmental Disabilities

Phone: (404) 498-3947  
E-Mail: [FASInquiries@cdc.gov](mailto:FASInquiries@cdc.gov)  
<http://www.cdc.gov/ncbddd/fas>

**When you are pregnant, drinking alcohol can hurt your baby!**

**Any amount of alcohol use during pregnancy has the potential to cause your unborn child a lifetime of physical and mental problems.**

This pamphlet was produced by the  
National Indian Justice Center  
For More Information on  
Fetal Alcohol Syndrome Awareness and Education  
Materials Contact:

5250 Aero Drive, Santa Rosa, CA 95403  
Phone: (707) 579-5507  
Fax: (707) 579-9019  
E-mail: [nijc@aol.com](mailto:nijc@aol.com)  
[Http://www.nijc.org](http://www.nijc.org)

## FAS/ARND

Fetal Alcohol Syndrome/  
Alcohol-Related Neurodevelopmental  
Disorders

- Drinking alcohol during pregnancy is the leading cause of **preventable** birth defects.
- FAS/ARND and other alcohol related disorders are entirely preventable by abstaining from alcohol during pregnancy.
- The rates of FAS among the American Indian population varies from tribe to tribe. For the overall population, FAS prevalence was 3.0 per 1,000 live-born infants for American Indians/Alaska Natives during 1977--1992. In some Indian communities rates are much higher. Southwest plains Indians report 1 incidence of FAS per 102 births.
- Everything you eat and drink while you are pregnant affects your baby. Drinking alcohol can affect your baby's growth. It can cause your baby physical and behavioral problems that will last a lifetime. It can harm your baby's brain even though he or she looks normal.

- **FAS/ARND is a challenge that lasts a lifetime.**

- **If you drink alcohol during your pregnancy your baby may be born with birth defects that will never go away.**

- **FAS/ARND threatens the health and vitality of our children, communities and culture.**



### Children whose mothers drink during pregnancy may be born with:

- Permanent brain damage
- Heart and other organ defects
- Height and weight deficiencies
- Problems hearing and seeing
- The need for special medical care throughout their lives

### These birth defects may result in:

- Problems eating and sleeping
- Learning disabilities
- Behavioral problems
- A need for special teachers and schools
- Trouble getting along with others and controlling their behavior

**Common questions about drinking alcohol during your pregnancy:**

**Can I drink alcohol while I am pregnant?**

No, you cannot drink alcohol while you are pregnant. If you are drinking alcohol, so is your baby.

**Is there any amount or type of alcohol that is safe to drink?**

Since everyone metabolizes alcohol differently, alcohol in any amount and of any kind has the potential to harm your baby.

**If I drank during my last pregnancy and my baby seems fine, is it okay to drink during this pregnancy?**

Every pregnancy is different. The impact of alcohol will affect each baby differently. Alcohol may cause visible defects in one baby, while another is born without visible defects. There is no way to predict the outcome. Not drinking is the only way to protect your children.

**Will these problems go away?**

No, the effects of alcohol exposure will last through-out the lifetime of the child. Children with FAS/ARND will require special care and treatment, and may not be able to care for themselves when they become adults.

**What if I am pregnant and have been drinking?**

Stop drinking now. Your baby will have a better chance of being born healthy. If you are planning a pregnancy, do not drink alcohol. You could become pregnant and not know it. Alcohol can harm a baby even if you are only one or two months pregnant when you drink.

**How can I stop drinking?**

If you need help, consult a doctor, nurse, spiritual advisor, or find a local clinic or program. Meanwhile don't let people pressure you into drinking. Try to stay away from people or places that tempt you to drink alcohol.

**Friends and family can show support through encouragement or joining the expectant mother in choosing to be alcohol-free!**