INTRODUCTION

This is the second in a series of State Issue Briefs prepared by the National Association of State Alcohol and Drug Abuse Directors (NASADAD) primarily for distribution to State Alcohol and Other Drug (AOD) Agencies through support from the National Institute on Alcohol Abuse and Alcoholism (NIAAA). These Briefs are unique in that they are not intended to be a comprehensive review of the science around a topic but rather a compilation of selected findings in an area and an exploration of the implications for administrators of AOD treatment systems.
BACKGROUND

At an April 2004 meeting sponsored by the National Organization on Fetal Alcohol Syndrome (NOFAS), experts from the National Institutes of Health, the Substance Abuse and Mental Health Services Administration, the Centers for Disease Control and Prevention, and NOFAS adopted the term “Fetal Alcohol Spectrum Disorders (FASD)” to describe the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. Rather, it is an umbrella term that encompasses the broad effects of prenatal alcohol exposure beyond the discrete diagnostic criteria for Fetal Alcohol Syndrome (FAS) or other defined disorders caused by prenatal alcohol exposure.

All Fetal Alcohol Spectrum Disorders are completely preventable – they do not occur among children born to women who abstain from alcohol during pregnancy. At this time there is no known safe level of alcohol consumption during pregnancy, and the amount and timing of alcohol consumption affects the severity and type of damage to the fetus. Structural damage to the central nervous system (CNS), leading to growth deficiency, facial defects, and neurodevelopmental and behavioral problems, occurs in some proportion of children who are exposed to alcohol before birth. These problems include reduced intellectual, cognitive, and motor functioning, as well as mental health problems and other deficits (National Institute on Alcohol Abuse and Alcoholism, 2000). The total lifetime cost of FASD – for treatment, lost productivity, and other societal costs -- has been estimated at about $2 million per affected individual (Lupton et al., 2004).

To help protect children from alcohol-related problems, all women should be made aware of the consequences of drinking alcohol during pregnancy. In addition, researchers, treatment professionals, and prevention practitioners must work together to develop prevention strategies that effectively target women at different levels of risk for alcohol use during pregnancy. Strategies for identifying and treating "high risk" women, for example, especially alcohol-abusing women who have had FAS children, need to be expanded. The effectiveness of various prevention interventions must be further evaluated so that the most beneficial ones can be identified for broad application. State AOD systems are in a unique position to support the adoption and expansion of effective and promising prevention and intervention approaches to reduce the consequences of prenatal exposure to alcohol, but evidence-based practices to achieve that end are still in short supply.
DEFINITIONS AND DIAGNOSES

The terminology used to describe the effects of prenatal alcohol exposure has changed over time (Hoyme et al., 2005). The effects of prenatal alcohol exposure, however, namely growth deficiency, CNS abnormalities, behavioral and/or cognitive developmental disorders, and characteristic facial defects, remain the same.

**Fetal Alcohol Syndrome (FAS)** describes a set of physical, mental, and neurobehavioral birth defects associated with alcohol consumption during pregnancy. Characteristic physical effects include small eye openings, low nasal bridge, short nose, small midface, thin upper lip, indistinct philtrum, skin folds at the corner of the eye, and small head circumference.

The **Institute of Medicine (IOM)** of the National Academy of Sciences developed a classification system to describe the effects of prenatal alcohol exposure (Stratton et al., 1996) that includes three separate FAS categories, each of which uses different combinations of FAS facial effects, confirmation of prenatal alcohol exposure, additional criteria on growth retardation, and CNS abnormalities, as well as evidence of behavioral or cognitive developmental disorder. Two additional categories in the IOM classification scheme are: **Alcohol Related Neurodevelopmental Disorder (ARND)** and **Alcohol Related Birth Defects (ARBD)**. ARND refers to the same defects that are seen in FAS, with the exception of FAS facial effects and growth retardation. ARBD includes physical birth defects associated with maternal alcohol consumption during pregnancy.

PREVALENCE

Prevalence is the proportion of a population that is affected with a particular disease. Researchers try to gauge the full extent of fetal alcohol problems by determining prevalence rates of FAS, ARND, and ARBD, through several kinds of studies.

In **passive surveillance**, researchers review multiple records to gather information on the number of diagnosed cases in a particular time frame and geographic area. **Clinic-based studies** involve collecting information from women during pre- and postnatal visits to health clinics, while **active case ascertainment** involves outreach efforts to find and recruit FAS children within a population being studied. A review of recent studies concluded that the overall prevalence of FAS in the United States is likely to be between 0.5 and 2.0 per 1,000 births (May & Gossage, 2001). Other studies estimate that 10 of every 1,000 babies will be born with either FAS, ARBD, or ARND (Abel, 1995, 1998; Sampson et al., 1997).
EFFECTS OF PRENATAL ALCOHOL EXPOSURE

Early research concluded that prenatal alcohol exposure produced widespread, or global, damage to the developing brain (Clarren, 1986). More recent studies, however, have demonstrated that prenatal alcohol damages specific areas of the brain. Using magnetic resonance imaging (MRI) to view the brains of children with FAS, these studies have shown that brain areas that regulate movement and cognitive processes related to attention, perception, thinking, and memory are particularly sensitive to prenatal alcohol exposure while other areas are not affected, and that overall brain size is reduced in children with FAS (National Institute on Alcohol Abuse and Alcoholism, 2000).

Studies have shown that alcohol exposure at different times during pregnancy damages different parts of the fetal brain and other organs (Coles, 1994; Goodlett & Johnson, 1999; Maier et al., 1996). The pattern of maternal drinking influences the extent of the damage. Binge drinking appears to be particularly harmful (Goodlett et al., 1997, 1998). Additionally, the harmful effects of alcohol may be enhanced by the use of tobacco and other drugs and by certain physiological characteristics of the mother (Abel & Hannigan, 1995; Maier et al., 1996; Phillips et al., 1989; Polache et al., 1996; National Institute on Alcohol Abuse and Alcoholism, 2000).

In addition to structural brain damage, prenatal alcohol exposure leads to developmental deficits in learning and memory, attention, and other cognitive functions, as well as problems with motor control, mental health, and psychosocial behavior in children with FAS and ARND.

Scientists have not established the minimum amount of alcohol needed to produce harmful effects in exposed children (Roebuck et al., 1999). Clearly, the safest approach is to completely avoid alcohol during pregnancy.

Indeed, in view of the expanding scientific evidence that prenatal alcohol use causes a wide range of harmful effects, the U.S Surgeon General released an Advisory in February 2005 urging women who are or may become pregnant to abstain from alcohol. The Advisory also calls on health professionals to routinely ask women of childbearing age about alcohol use and to inform them of the risks of alcohol consumption during pregnancy. The 2005 Advisory updated a 1981 Surgeon General’s Advisory that called for pregnant women to avoid alcoholic beverages and to be aware of the alcoholic content of foods and drugs.
PREVENTION APPROACHES

Since all fetal alcohol problems are preventable, finding effective ways to help women at all levels of risk refrain from drinking alcohol during pregnancy is a top priority. A variety of approaches have been developed and used thus far, including:

1) comprehensive and coordinated treatment, in which a case manager helps a woman obtain social, medical, referral, outreach, and family support, as well as counseling services. Finkelstein (1993) found that this can be an effective approach for high-risk women.

2) the public health approach, which incorporates three levels of interventions along a prevention continuum:
   - Primary approaches focus on stopping maternal drinking before problems arise;
   - Secondary approaches involve early detection and intervention targeted to pregnant women with drinking problems; and
   - Tertiary approaches address the need to change the behavior of high risk women - especially those who already have children diagnosed with FAS, ARND, or ARBD.

An Institute of Medicine (IOM) Committee to Study Fetal Alcohol Syndrome has recommended three prevention approaches – each corresponding to a different level of risk for drinking during pregnancy (Stratton et al., 1996).

   - The universal prevention approach involves informing and educating the public and influencing public policies and thus targets all women;
   - The selective prevention approach delivers interventions to groups that may have increased risk for fetal alcohol problems such as women of childbearing age who drink; and
   - The indicated prevention approach targets groups that have a very high degree of risk. Pregnant women who are drinking heavily, or who previously have given birth to a child with FAS, fall under this category. For such women, the IOM Committee recommends the use of brief interventions or more intensive forms of substance abuse treatment.
EFFECTIVENESS OF PREVENTION APPROACHES

The universal prevention approach is thought to be an effective way to make women aware of the adverse effects of prenatal alcohol exposure. Messages are delivered through a variety of sources such as radio, television, printed material, and on labels on alcoholic beverages (National Institute on Alcohol Abuse and Alcoholism, 2000). For example, the NIAAA and the National Organization on Fetal Alcohol Syndrome (NOFAS) conducted a two-year pilot program that targeted African American women of child bearing age in Washington DC and sent the message, “Play it safe. Alcohol and pregnancy don’t mix,” through media messages, special events, and community activities (National Institute on Alcohol Abuse and Alcoholism, 2002). Most women reduce their drinking or abstain from drinking when they become pregnant (Kaskutas & Graves, 1994). Several studies show that labels on alcoholic beverages have a positive effect on women who are light drinkers but not on women who are heavy drinkers, and that a similar positive effect is produced by warning signs on buses and billboards (Fitzgerald, 1988; Hankin, 1994; Hankin et al., 1993, 1996; Little et al., 1981, 1984, 1985; Weiner et al., 1989). Other research has shown that screening alone can reduce drinking among some pregnant women (Whalen & O’Connor, 2003). Women who drink heavily and have been drinking for a long time, and become pregnant demonstrate the smallest amount of change in drinking patterns (Serdula et al., 1991; Smith et al., 1987).

Selective prevention approaches that address prenatal alcohol concerns, target special populations, and include non-treatment interventions have been widely used. Few, however, have been adequately evaluated for effectiveness (Stratton et al., 1996; National Institute on Alcohol Abuse and Alcoholism, 2000). Women who have an increased risk of having alcohol-impaired children may be identified through the use of screening procedures in primary care and prenatal care clinics (Chang et al., 1997; Hankin & Sokol, 1995; Harwell et al., 1996; Kaskutas, 1996; Loneck et al., 1997) and their readiness to change should be assessed (Kaskutas, 1996). NIAAA has supported the development of computer-assisted screening instruments, and a number of studies have shown the utility of this approach. Commonly used screening instruments such as the CAGE, T-ACE, TWEAK, and MAST may be less accurate in some populations of women than in others (Bradley et al., 1998; Ewing, 1984; Sokol et al., 1989; Selzer, 1971; Chan et al., 1993). Therefore, reliable screening instruments for women of childbearing age who may have drinking problems are an important area for research and development (Chang et al., 1998). Interventions that could be offered to such women might include providing educational materials and conducting a brief counseling session.

Indicated prevention approaches have been designed to reach women at highest risk for alcohol-exposed pregnancy – those who are heavy drinkers, pregnant, and who may already have a child diagnosed with FASD. Little is known, however, about the effectiveness of these programs (National Institute on Alcohol Abuse and Alcoholism, 2000). Low socio-economic urban areas (Abel, 1995) and high-risk American Indian communities have the highest rates of FASD (Duimstra et al., 1993; May, 1991; Qaid et al., 1993; Robinson et al., 1987). Indicated prevention strategies include:
• **Intensive case management** (Bacon, 1988; Davis and Frost, 1984; Masis & May, 1991; Rosett et al., 1981; Stratton et al., 1996; Weiner et al., 1989). Case management tailors care to the specific social and medical needs of the woman, her family, and her children. This approach coordinates substance abuse care across various institutions and agencies and involves all members of the extended family. In particular, the positive action of the male partner should be enlisted;

• **Alcohol interventions** combined with strategies to reduce unplanned pregnancies (Masis & May, 1991; May, 1995);

• **Motivational therapy sessions** in prenatal clinics (Handmaker & Wilbourne, 2000);

• **Brief interventions** and referrals to traditional treatment programs (Stratton et al., 1996); and

• **Aftercare programs** (Klein & Zahnd, 1997; Kaskutas, 1996).

**Comprehensive treatment programs** that provide other services such as medical and obstetric care have been found to be effective for women who do not respond to other types of intervention (Finkelstein, 1993; Jessup & Green, 1987; Rosett & Weiner, 1981; Stratton et al., 1996). In addition, extensive aftercare services for women who have given birth to a child with FAS show promise for preventing subsequent FAS births.

### IMPLICATIONS FOR STATE AOD PREVENTION AND TREATMENT SYSTEMS

Virtually all States have programs in place to address at least some aspects of FASD reduction. Some of these initiatives -- warning labels on alcohol beverage bottles and mandatory warnings posted in alcohol outlets, for example -- lie outside the purview of the State AOD Agency. For the most part, however, FASD reduction activities at the State level can be directly attributable to the action of State AOD Agencies and their provider networks. In a significant number of States, efforts to reduce FASD encompass programs across the entire continuum of primary prevention, early intervention, and treatment.

The actual practices incorporated in State level FASD programming have seldom been rigorously evaluated and, in some cases, have not been reviewed recently for content, extent of desired coverage attained, appropriateness of implementation, or to determine if there are service gaps along the continuum.

State AOD Agencies may wish to consider:
• Establishing focused treatment aftercare programs for treatment program graduates who have given birth to one or more children with FASD. Such programs should include coordination with primary health care, social and vocational support services and family/marriage counseling services at a minimum;

• Encouraging and supporting the development and implementation of “in reach” protocols at all venues in which health care providers may come in contact with women who may be at high risk for having (or who already may have) a child with FASD. The literature suggests that such programs could be especially effective within public health settings. “In reach” may be thought of as the practice of piggy-backing a prevention intervention on a patient or client visit scheduled for another purpose. Health care personnel involved must be trained in AOD screening, brief interventions, and referrals to treatment;

• Reviewing and revising licensure/accreditation standards for prevention and treatment providers, as necessary, to ensure that they incorporate appropriate provisions for the provider’s role in reducing the incidence of FAS and other negative consequences of prenatal exposure to alcohol;

• In working with State mental health authorities who deliver services to clients with co-occurring substance abuse and mental health disorders, State AOD Agencies should emphasize the importance of ensuring that mental health facilities routinely identify women at high risk of having an FASD child and are capable of providing appropriate services; and

• Identifying and developing joint or complementary programming around FASD reduction with other relevant State and local agencies and organizations, e.g., the recipient of the Maternal and Child Health Block Grant; State Educational Authorities; Women, Infants and Children (WIC) clinics, etc.

**FUTURE RESEARCH**

More FASD reduction research is needed (National Institute on Alcohol Abuse and Alcoholism, 2000) to advance the current state of knowledge and to arm State systems with interventions that are demonstrably efficient and effective. Key elements for future FASD prevention research include: refining prevalence estimates; precisely articulating social and medical risk factors; obtaining further information on the role of the male partner in reducing risk; developing accurate instruments for identifying high-risk women; and expanding community trials (May, 1996). Specific topics for further study might include:

• Matching effective therapies with subtypes of women (Loneck et al., 1997; Peterson & Lowe, 1992);
• Assigning clients to brief versus extended interventions, and examining coercive versus voluntary treatment (Miller & Rollnick, 1991);

• Investigating the relative merits of group versus individual therapy (Stratton et al., 1996); and

• Evaluating case management models, environmental change techniques, and support groups for FAS mothers (Meyers & Smith, 1995; Meyers et al., 1996).

NIAAA encourages research that provides comparative information on new interventions and existing practices. Such information helps State-level decision-makers allocate resources and also helps to promote the timely dissemination and adoption of research-based FASD interventions.

REFERENCES


About the National Institute on Alcohol Abuse and Alcoholism (NIAAA)

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) supports and conducts biomedical and behavioral research on the causes, consequences, treatment, and prevention of alcoholism and alcohol-related problems. NIAAA also provides leadership in the national effort to reduce the severe and other fatal consequences of these problems.

NIAAA is one of 27 Institutes and Centers that comprise the National Institutes of Health (NIH), the principal biomedical research agency of the Federal Government, charged with uncovering new knowledge that will lead to better health for everyone. NIH is a component of the Public Health Service within the Department of Health and Human Services.

Visit the NIAAA website at http://www.niaaa.nih.gov/

About the National Association of State Alcohol and Drug Abuse Directors, Inc. (NASADAD)

NASADAD is a private not-for-profit educational, scientific, and informational organization that was established in Washington, D.C. in 1971 to represent Directors of State Alcohol and Drug Abuse Agencies. NASADAD’s basic purpose is to foster and support the development of effective alcohol and other drug abuse prevention and treatment programs throughout every State. NASADAD serves as a focal point for the examination of alcohol and other drug related issues of common interest for both State and Federal Agencies.

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