



Preventing Fetal Alcohol Spectrum Disorders Starts with Young Girls

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The Maternal and Child Health Bureau's succinct version of the life course perspective, divided into four key concepts—**timeline**, **timing**, **environment**, **equity**—was created specifically to guide the work of public health professionals. (See “Life Course Perspective: A Summary of Rationale and Resources,” in [Emerging Issues in Maternal and Child Health](#).) While providing specific information about issues of concern related to women and alcohol consumption, articles in this issue also illustrate this perspective. For example, the age at which a person starts to drink (**timing**) is a strong predictor of the development of an alcohol problem later in life, with those who start drinking before the age of 15 five times more likely to develop a problem than those who wait until the age of 21. Considering this, it is of concern that the percent of young girls reporting drinking alcohol before the age of 13 has increased. Lauri Turkovsky, in her editorial, describes current influences related to this increased consumption and prevention activities that address risk factors unique to girls.

Fetal alcohol syndrome is the leading known cause of mental retardation and developmental disabilities in the United States (**timeline**). Carolyn Hartness defines the various diagnoses included under the term “fetal alcohol spectrum disorders” and describes prevention activities (**environment**). She emphasizes that because it is impossible to predict the damage to the fetus caused by alcohol, drinking at any time during pregnancy is unsafe.

Two researchers contribute to this issue: Debra Kaysen describes the latest research on the link between alcohol abuse and sexual and physical victimization and Sherry Lipsky examines recent research on the role that race, ethnicity, and sexual minority status play in alcohol abuse (**equity**).

Also in this issue is an article about what it's like to raise a child with fetal alcohol syndrome. Julie Gelo and her husband are legal parents to 16 children, 11 of whom have fetal alcohol syndrome or a related condition. She describes her experiences raising one of those 11 children, Brandan, and the persistence and creativity needed to obtain support and services for him.

Northwest states report on successful prevention programs and activities, and results from surveys and needs assessment (**environment**). ❖

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Updates

We'd like to welcome Michele Maddox, PhD, RN, as the Washington State representative to the editorial board. Michele is the Legislative, Communication, and Maternal and Child Health Block Grant Coordinator for the Washington State Department of Health. Prior to that, she was a senior evaluator at Prometric, a contractor for the Washington State Department of Health to provide Home Health Care Aide Certification.

Reader Information

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Editorial . . .

Young Girls and Alcohol

Positive Relationships Key to Preventing Early Initiation of Drinking

Lauri Turkovsky

The age at which a young person starts to use alcohol is a strong predictor of the development of an alcohol addiction. Youth who start drinking before age 15 are five times more likely to develop a disorder than those who wait to drink alcohol until at least age 21.(1) For this reason, prevention strategies often focus on youth, aged 11 to 14 years, and on four domains most salient in a young person's life (see side bar, page 5).

Why Young Girls Drink

The National Survey on Drug Use and Health, conducted annually since 1991, documents a number of trends in alcohol and other drug use behaviors.(2) For example, in the 1960s, only 7% of girls reported they had their first drink of alcohol between the ages of 10 and 14. Today, 18% of girls report drinking alcohol before the age of 13. Several factors appear to be related to increased alcohol use among girls.

Early Age at Menarche. Those with menarche before age 12 are more likely to report that they drank beer before the age of 12 and to be weekly drinkers than those with menarche at age 14 or later.(3)

Victimization and Psychological Distress. Girls who have been sexually or physically abused are twice as likely to use alcohol as girls who have not been abused.(3)

Depression and suicide. Girls are significantly more likely to experience symptoms of depression and suicidality than boys.(3) While these problems are associated with higher levels of drinking, the initiating factor is unclear. Parents, educators, and other professionals working with youth have long assumed that depression causes individuals to drink as a form of self-medication. Recent research suggests that substance abuse may be the original cause of depression.

Concerns about appearance. Girls who report being highly concerned about their weight are almost twice as likely to get drunk as those reporting less concern.(3)

Media influence. The media does have



an influence on adolescent alcohol use, with boys more influenced by sports-related alcohol commercials and girls more susceptible to alcohol commercials that make drinking appear fun and sexy.(4)

Stars curriculum also includes lessons to correct adolescents' misperceptions of peer alcohol use, which helps decrease early initiation.(5) Evidence indicates a gender-segregated substance-abuse prevention curricula may be more helpful for girls than the standard mixed-gender curricula.(6)

Adults, particularly adult women, parents, and health care providers can have a powerful positive influence on girls' choices regarding drinking alcohol

Girls are influenced heavily by those with whom they have relationships. Adults, particularly adult women, parents, and health care providers can have a powerful positive influence on girls' choices regarding drinking alcohol. Programs similar to

Relational Influences

Of the risk factors identified by Hawkins and Catalano (see side bar, page 5), those that are relational have a stronger influence on girls than boys.

Family. Family supervision and support are especially important in preventing alcohol use among girls. Those who have a close relationship with their parents are less likely to use alcohol for fear of disappointing them. Alcohol use in boys, however, is often associated with a family history of alcoholism.(3, 4)

School. Girls who are positively connected to their school do better academically than girls who are not. This is particularly important because academic success decreases the risk for alcohol abuse in adulthood.(3)

Individual and Peer. Girls are especially vulnerable to alcohol-related peer pressure while boys tend to drink to have fun.(2, 4) Strikingly, a girl is more than seven times more likely to drink alcohol when several of her closest friends drink, whereas having close friends who drink relates to a boy being only three times as likely to drink.(3)

Community. Health care providers have a particularly influential role on girls and their decisions about drugs and alcohol.(3) In fact, girls report that drinking is one of the top ten health topics they wish their doctors would address during clinical visits. Unfortunately, 67% of girls report that their providers pass up these opportunities to educate their young female patients about drinking.(3)

Prevention

Schools can implement research-based prevention curricula such as [All Stars](#), [Project Northland](#), and life skills training, which address topics such as peer pressure, decision making, and resistance skills. The All

Big Brothers Big Sisters can provide the extra support to youth who need it. While it's likely that both girls and boys benefit from the extra positive adult attention, it may be especially important for girls.❖

Lauri Turkovsky, EdD, works with state-funded fetal alcohol spectrum disorder prevention programs at the Division of Behavioral Health and Recovery, Washington State Department of Social and Health Services. She has 20 years of experience in the field of prevention: eight in HIV and STD prevention and 12 in research-based substance abuse prevention. She has expertise in curricula implementation, social marketing, strategic prevention planning, and prevention program evaluation.

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3. Fact Sheet: Girls and Alcohol. The National Center on Addiction and Substance Abuse at Columbia University, 2007. www.casacolumbia.org/articlefiles/412-GIRLS%20AND%20ALCOHOL_CASA%20Fact%20Sheet.pdf
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6. Shinke S, Scwinn T. Gender-specific, computer-based intervention for preventing drug abuse among girls. *Am J Drug Alcohol Abuse*. 2005;31(4):60916.

Resources

- Preventing Heavy Alcohol Use Among Girls and Young Women: Practical Tools and Resources for Practitioners and Girls' Programmers
The British Columbia Centre for Excellence for Women's Health
www.bcccewh.bc.ca/news-events/documents/BC-CEWHPreventingHeavyAlcoholUseAmongGirlsYoungWomen_PracticalToolsResourcesforPractitionersGi.pdf
- Prevention of Substance Abuse and Mental Illness, Strategic Prevention Framework
Substance Abuse and Mental Health Services Administration
www.samhsa.gov/prevention/spf.aspx
- Strategic Planning Coalition for Families and Youth (SPIFFY)
<http://spiffycoalition.org/educators/school-programs>
- Substance Use Among Young Mothers
National Survey on Drug Use and Health Report
www.oas.samhsa.gov/2k11/196/YoungMothers.htm

Girls' Risk Factors for Substance Abuse

Research over the past twenty years has focused on understanding the determinants of substance abuse. Not surprisingly, neither a poor moral character nor a lack of will-power were identified.

Pioneering research by University of Washington researchers David Hawkins and Richard Catalano led to the development of a profile of risk factors in four domains most salient to a young person's life. A more complete discussion of risk and protective factors can be found at www.SDRG.org.

Family:

- ◆ Family history of substance abuse
- ◆ Poor family management
- ◆ Family conflict
- ◆ Lack of rules against drug and alcohol use
- ◆ Family including youth in drug and alcohol use

School:

- ◆ Lack of commitment to school
- ◆ Academic failure

Individual and Peer:

- ◆ Early and persistent anti-social behavior
- ◆ Extreme rebelliousness
- ◆ Friends who use drugs and alcohol
- ◆ Use of alcohol before age 13
- ◆ Gang involvement

Community:

- ◆ Availability of drugs and alcohol
- ◆ Laws and norms favorable to use
- ◆ High mobility at school and home
- ◆ Low attachment to nurturing communities
- ◆ Poverty

Fetal Alcohol Spectrum Disorders

Definition, Behaviors, Prevalence and Cost, and Prevention

Carolyn Hartness

Over the years, many terms have identified the consequences of alcohol exposure to the fetus. The term “fetal alcohol spectrum disorders,” adopted in 2004, is not a diagnosis: it is an umbrella term for various diagnoses of fetal alcohol exposure using different diagnostic models. These diagnoses include:

- ◆ Fetal alcohol syndrome (FAS): growth deficiency, unique cluster of minor facial anomalies (shortened eyes slits, indistinct philtrum, thinned upper lip), central nervous system damage (structural, neurological, and functional impairment), prenatal alcohol exposure
- ◆ Partial FAS: most, but not all, of growth deficiency and FAS facial features, central nervous system damage (structural, neurological, and functional impairment), prenatal alcohol exposure
- ◆ Alcohol-related neurodevelopmental disorders: central nervous system damage (structural, neurological, and functional impairment), prenatal alcohol exposure
- ◆ Static encephalopathy (alcohol exposed): central nervous system damage (structural, neurological, and significant functional abnormalities), prenatal alcohol exposure
- ◆ Neurobehavioral disorder (alcohol exposed): central nervous system dysfunction (mild functional impairment with no evidence of structural or neurological abnormalities), prenatal alcohol exposure

There are also a range of alcohol-related birth defects, such as physical or cognitive deficits, which can range from mild to severe, including conditions with one or more congenital defects.

In recommended practice, an interdisciplinary team carries out a diagnostic screening. This team consists of a specially trained physician and often a psychologist, speech pathologist, and occupational therapist. Sometimes professionals qualified to conduct or decipher a neurodevelopmental assessment participate.



Whether or not FAS features are present, everyone with an FASD exhibits some level of brain damage. A diagnosis and an understanding of child development are essential to the assessment and reframing of behaviors. This birth defect can not be “fixed.” Drinking at any time during pregnancy is potentially dangerous to the fetus. Because predicting the damage caused by alcohol is impossible, there is no safe amount.

Planned pregnancy and education about the dangers of drinking during pregnancy are unequivocally the best strategies to prevent these birth defects

Research and experience clearly demonstrate that an early diagnosis is essential to successful interventions for individuals exposed to alcohol in utero. Diagnoses guide families and providers in establishing appropriate services. Individuals without the physical characteristics of FAS may find it more difficult to access services than those with visible disabilities.

Behavior and Appropriate Strategies

Understanding which areas of the brain are damaged by alcohol exposure is crucial to establishing realistic interventions for affected individuals and expectations for caregivers. Cognition, academic achievement, adaptive skills, executive functioning, motor and sensory integration, attention and memory, language and social communication can all be affected.

Behavior, not facial features, usually drives caregivers to seek a diagnosis. After a positive diagnosis, caregivers and providers must change their assumptions about what behaviors are communicating. Specific diagnoses are essential to delivering effective and appropriate interventions. For example, a behavior may indicate the affected person is overstimulated instead of willfully destructive, lazy, or uninterested.

Individuals with FASD tend to be concrete thinkers and have difficulty with abstraction. Structured environments and activities that provide predictability and consistency work best. Creating uncluttered spaces with muted colors, giving one direction at a time, and establishing schedules are examples of appropriate strategies.

Prevalence and Cost

Fetal alcohol syndrome is the leading known cause of

mental retardation and developmental disabilities in the United States. Prevalence is estimated to be 0.5 to 2.0 cases per 1,000 live births, though estimates vary widely due to variations in study populations, case definitions, and study methodologies. Recent data from the Fetal Alcohol Syndrome Surveillance Network estimates prevalence at 0.3 to 1.5 cases per 1,000 live births in certain areas in the United States. (1)

High costs related to social services, special education, and legal, medical, and mental health expenses are common for this population.

Loss of productivity of care providers is more difficult to calculate but is also part of costs. Lupton compared results of studies conducted between 1980 and 1992 while adjusting estimates to 2002 dollars, using treatment and care costs only and assuming a prevalence rate of 2 cases per 1,000 live births. He found that annual cost estimates ranged from \$2.3 billion to \$11.1 billion in the United States.(2)

Prevention

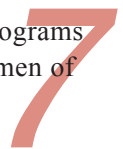
Fetal alcohol spectrum disorders cross all racial, social, and economic lines and are directly linked to unintended pregnancies. Planned pregnancy and education about the dangers of drinking during pregnancy are unequivocally the best strategies to prevent these birth defects.

Primary prevention activities focus on:

- ◆ Encouraging the use of family planning among women of childbearing age and women who are at high risk for giving birth to a child with FASD, including those who abuse and depend upon alcohol and birth mothers of children with FASD
- ◆ Promoting healthy behaviors and pre-conception care for women of child-bearing years, including abstinence from alcohol prior to pregnancy
- ◆ Educating the public, particularly young people, about the dangers of drinking during pregnancy
- ◆ Creating social marketing campaigns to discourage harmful drinking in the general population

Secondary prevention activities focus on:

- ◆ Screening as well as early intervention programs and services for pregnant women and women of



childbearing age who may be at risk for having a child with an FASD

- ◆ Treatment programs to effectively help women with a substance abuse problem who are pregnant or who have already delivered a child exposed to or affected by alcohol
- ◆ Increasing collaboration between general practitioners, maternity and newborn service providers, and alcohol and other substance abuse services to ensure comprehensive drug and alcohol maternity services for all pregnant women

Tertiary prevention activities focus on:

- ◆ Identifying barriers to accessing antenatal care and treatment by women with alcohol-related dependency
- ◆ Implementing routine screening of pregnant women who use alcohol
- ◆ Establishing early interventions to assist affected individuals avoid the serious effects of secondary disabilities resulting from the cognitive, behavioral, and social impact of FASD, such as disrupted school attendance and trouble with the law

The most powerful prevention message is that FAS is 100% preventable. ❖

Carolyn Hartness is a fetal alcohol spectrum disorders educator and consultant. Since 1991, she has presented at conferences and trained and consulted throughout the United States and internationally. She is a trainer for the University of Washington FAS Center for Excellence and also consults with agencies, schools, and organizations. Carolyn co-authored the Emmy-nominated series, Journey Through The Healing Circle, with Robin LaDue, and authored the manual, Alcohol and the Fetus.

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Resources

The ARC of the United States (A National Organization on Mental Retardation)

www.thearc.org/

The Fetal Alcohol and Drug Unit (University of Washington)

<http://depts.washington.edu/fadu>

Fetal Alcohol Spectrum Disorders, Centers for Disease Control and Prevention

www.cdc.gov/ncbddd/fasd/index.html

Fetal Alcohol Syndrome

Alcohol Policies Fact Sheet

Center for Science in the Public Interest

www.cspinet.org/booze/FactSheets/031124FAS.pdf

The National Institute on Alcohol Abuse and Alcoholism's Alcohol Alert No. 50: Fetal Alcohol Exposure and the Brain

<http://pubs.niaaa.nih.gov/publications/aa50.htm>

The National Organization on Fetal Alcohol Syndrome (NOFAS)

www.nofas.org/

SAMHSA Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence

<http://fascenter.samhsa.gov/>

Substance Use During Pregnancy

MCH Library

The Maternal and Child Health Library at Georgetown University

www.mchlibrary.info/databases/bibliography.php?target=auto_search_subusepreg

Women and Alcohol Abuse

The Role of Victimization and Psychological Distress

Debra Kaysen

Although there are many reasons why women drink, the role of victimization and psychological distress is particularly striking in many of their stories. There are complex relationships between drinking behavior, risk of interpersonal victimization, emotional pain, and risk of future victimization. Research is increasingly focused on trying to better understand these relationships so we can help break this cycle.

Alcohol Use in Women

Until recently, much of what was known about alcohol use and alcoholism was based on research conducted solely with men. More recent research has attempted to improve our understanding of the role alcohol plays in women's lives.

Overall, women do tend to drink less than men. However, among those who drink most heavily, women have as many or more problems than men.(1) Alcohol consumption has increased among young women over the past ten years. Forty-two percent of college women say they drink to get drunk and 21% report binge drinking.(2) Thirty-seven percent of 9th grade girls report drinking in the past month, which is slightly higher than the rate of drinking for 9th grade boys. About 17% of these girls report binge drinking over the past month.(3) In addition, because of women's overall smaller size and lower fluid content, women will generally become more intoxicated on a much smaller dose of alcohol. If a woman is matching drinks with a man, she may become more intoxicated.

Alcohol and Trauma

Alcohol use has been found to be a risk factor for interpersonal violence among women.(4) Over half of victims of intimate partner violence report that the offender was drinking at the time. Similarly, the majority of sexual assaults involve alcohol use by the perpetrator, victim, or both. Binge drinking and heavy drinking both appear to increase risk of sexual victimization. Those with little experience with drinking appear to be at especially high risk for sexual victimization when drinking heavily.(5)

Women experience interpersonal victimization—child sexual abuse, sexual assault, and intimate partner violence—far more frequently than men. These traumatic stressors are also associated with some of the highest rates of Posttraumatic Stress Disorder (PTSD), as compared to other

Up to 80% of women seeking treatment for alcohol problems report histories of sexual or physical victimization.



traumatic events.

The link between PTSD and increased risk for alcohol problems overall appears to be stronger for women than for men. One large study found that 28% of women with PTSD, as compared to 14% without, were more likely to abuse or depend upon alcohol.(6) Another study found that depression appears to increase risk of later drinking problems in adolescents who were sexually or physically abused.(7)

Treatment

Up to 80% of women seeking treatment for alcohol problems report histories of sexual or physical victimization. For those with PTSD, the combination of PTSD and drinking problems can be challenging for both women seeking treatment and for treatment providers.(8)

Researchers and clinicians increasingly believe that treating both PTSD and drinking problems at the same time may be the best option for many women. Although few studies have examined whether women respond as well to alcohol treatment as do men, women appear to present less frequently for treatment but do appear to respond as well. ❖

Debra Kaysen, PhD, is a clinical psychologist and associate professor with the Department of Psychiatry and Behavioral Sciences at the University of Washington. Dr. Kaysen specializes in treatment of PTSD using empirically based interventions. Her research predominantly focuses on interactions between exposure to trauma, PTSD, and alcohol problems in women.

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Resources

Association for Behavioral and Cognitive Therapy

www.abct.org/Home/

National Centers for PTSD

www.ptsd.va.gov/public/index.asp

National Institute on Alcohol Abuse and Alcoholism

www.niaaa.nih.gov/

National Online Resource Center on Violence against Women

www.vawnet.org/

National Violence against Women Prevention Research Center

www.musc.edu/vawprevention/

Office on Violence against Women at the U.S. Department of Justice

www.ovw.usdoj.gov/

Rape, Abuse, & Incest National Network

www.rainn.org/index.php

Disparities in Alcohol Use Among Women

Sherry Lipsky

Women have long been thought to be lighter drinkers than men, and the statistics bear this out: adult men are two to three times more likely than women to have an alcohol use disorder (alcohol abuse or dependence).(1) Nevertheless, nearly one-fifth of adult women in the United States have had an alcohol use disorder in their lifetime. Women belonging to racial, ethnic, and sexual minority groups are at increased risk. Stress resulting from prejudice and discrimination may contribute to their risk.

Race and Ethnicity

Race and ethnicity play a major role in alcohol use, not only in terms of prevalence but also in trends over time. While women in most racial and ethnic minority groups are less likely to have abused alcohol in the past year (1.1% -1.7%) compared to non-Hispanic whites (2.9%), the prevalence of alcohol abuse is highest among Native American women (4.2%).(2) In addition:

- ◆ Past year alcohol abuse among non-Hispanic white, black, and Hispanic women and among young adult Asian women has significantly increased over time (2)
- ◆ Rates of alcohol dependence are highest among women in the reproductive years, especially young adults aged 18 to 29 years (2)
- ◆ A substantial proportion of ethnic minorities drink not only during pregnancy and the perinatal period, but also binge drink (3)

Nativity and acculturation also appear to affect rates of alcohol use disorder, with higher rates among Hispanics and Asian-Americans born in the United States compared to those born outside of the country.(4,5) Among women, higher acculturation has been associated with higher probabilities of drinking, higher volumes of alcohol consumption, and more frequent drinking to drunkenness.(6)

Sexual Minorities

Addressing sexual minority health and health disparities has recently become a public health priority as evidenced by the historic inclusion of health goals for lesbian, gay, bisexual, and transgender individuals in



Healthy People 2020. Lesbians and bisexual women appear to be at greater risk of misusing alcohol compared to heterosexual women:

- ◆ Women with same-sex partners are more likely to abuse or become dependent on alcohol earlier in life and have persistent alcohol dependence than women with different-sex partners (7)
- ◆ Women who identify as ‘mostly heterosexual’ or bisexual have higher rates of binge or hazardous drinking compared to exclusively heterosexual women
- ◆ ‘Mostly heterosexual’ and bisexual adolescent females are more likely than their exclusively heterosexual counterparts to report a younger age at first drink (8)

Disparities in alcohol use may be explained in part by stress resulting from prejudice and discrimination. Interpersonal as well as institutional discrimination have been demonstrated to play a significant role in alcohol use among racial, ethnic, and sexual minorities. Being alert to these risk factors for alcohol misuse, even though not all are modifiable, enables health care providers to provide more culturally sensitive and specific care. ❖

Sherry Lipsky, PhD, MPH, is a Research Assistant Professor at the UW Harborview Medical Center. She received her PhD in Epidemiology, MPH in Health Services-International Health, and Physician Assistant certificate from the UW. Dr. Lipsky’s research, funded by the NIH and ABMRF, the Foundation for Alcohol Research, focuses on health disparities in the relationship between intimate partner violence (IPV), mental health, and alcohol use. Her current work examines the temporal relationships between IPV, PTSD and alcohol outcomes.

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Resources

Screening for alcohol use and alcohol-related problems. Alcohol Alert. April 2005, No. 65. Available at: <http://pubs.niaaa.nih.gov/publicatons/aa65/aa65.htm>

Assessing Alcohol Problems: A Guide for Clinicians and Researchers. Second Edition, Revised 2003, NIH Publication No. 03-3745. Describes a range of screening instruments, including their target audiences, reliability, clinical utility, and research applications. Available at: <http://pubs.niaaa.nih.gov/publications/Assesing%20Alcohol/index.htm>

Helping Patients Who Drink Too Much: A Clinician’s Guide. 2005 Edition. NIH Publication No. 05-3769. Provides useful materials for screening, assessing, and administering brief interventions. Includes medication information and handy pocket guide. Available at: http://pubs.niaaa.nih.gov/publications/Practitioner/Clinicians-Guide2005/clinicians_guide.htm

U.S. Department of Health and Human Services. A Provider’s Introduction to Substance Abuse Treatment for Lesbian, Gay, Bisexual, and Transgender Individuals. HHS Publication No. (SMA) 09-4104; 2009. Available at: <http://kap.samhsa.gov/products/manuals/pdfs/lgbt.pdf>

Many Doors, No One Master Key:

Using Persistence and Creativity to Find Support and Services for Children with FASD

Julie K. Gelo

Raising a child with a fetal alcohol spectrum disorder (FASD) has many rewards, but these rewards are often accompanied by feelings of guilt and shame, financial strain, frustrations with the lack of knowledgeable professionals, and stress related to the child's involvement in the judicial system.

The types and depth of services available for affected children vary greatly, depending on where the child lives and the range of services available in that area. In addition, the majority of children with FASD are being raised by foster or adoptive parents. Many of these families are large and their children have different levels of disabilities, each with their own special needs. Meeting these needs requires high levels of structure and organization on the part of the caregiver.

Brandan's Story

When the foster care placement desk called and asked us to take placement of Brandan, an eight-day-old infant, we were better prepared than many families for a child with special needs. I have a medical background, we had been foster parents for three years, and eight of our foster children had been seen at the University of Washington FAS Diagnostic and Prevention Network clinic in Seattle. Brandan had a known exposure of daily amounts of alcohol in utero and was born as a breech delivery, growth deficient, and experiencing respiratory distress, seizures, as well as feeding problems.

Brandan's condition was diagnosed as full fetal alcohol syndrome at three months of age and we were given specific recommendations for his care. It was this diagnosis that enabled us to access needed services.

He weighed only 11 pounds when he was one year old, was tube fed his entire first year in an attempt to get him to grow and to give him his medications, and did not crawl until he was 14 months old. He suffered multiple respiratory, sinus, and ear infections and has had many ear surgeries. For the first three years of his life, he was seen by a specialist or therapist at least once a day nearly every day of the week. He continues to qualify for speech and language, and occupational and physical therapies.

Brandan: "This has just been the most beautiful day"



Brandan has received special education services all through his life, from a birth-to-three program to now in high school. His cognitive and academic challenges are profound. However, he shares with the world a unique and amazing sense of joy. One of his common statements is “this has just been the most beautiful day.”

nominal pediatrician, drum and banjo teachers, a special education teacher who is always open to learning, a band teacher who makes sure that Brandan is able to shine and is included in all events, and a group of amazing friends at school, including cheerleaders and band members. He has been selected by his band classmates as the most inspirational student for two consecutive years. This support network is truly the most important intervention and support in Brandan’s life. ❖

While a diagnosis of FAS may help in obtaining access to programs and services, we often get better results if we discuss the unique needs and strengths of our child with FASD

Creating a Support Network

My experience has been that while Washington State leads the nation in the areas of diagnosis and research, we often lack specific intervention services for individuals with FASD. This has required persistence and creativity on my part in finding support and services for my children and my family. In 2003, a friend and I wrote a grant proposal requesting funding for a three-day summer camp for children with FASD and their families. Those three days were among the most encouraging and positive days our family and the 12 other families have had.

Out of that camp a support network was formed that eventually became [NOFAS Washington State](#), the state’s affiliate to the National Organization for Fetal Alcohol Syndrome. Along with a powerful board of directors and passionate families, we created online and face-to-face support groups for caregivers, parents, and community providers; one-day conferences; a teen social skills group; a friendship group for children in elementary school; and a 5-day family summer camp for five more years.

The formation of these programs and creation of this support network has been our lifeline these past years. Unfortunately, due to state budget cuts, our affiliate organization no longer receives state funding.

Beyond a Diagnosis

It has been my experience that while a diagnosis of FAS may help in obtaining access to programs and services, we often get better results if we discuss the unique needs and strengths of our child with FASD. This allows us to cultivate relationships with interested and caring people willing to listen and to learn.

Brandan’s support team now consists of a phe-

Julie Gelo and her husband are legal parents to 16 children, aged 6 to 45 years. They have been licensed foster parents for 20 years. Eleven of the children have fetal alcohol syndrome or a related condition, including all seven who live at home. Julie is the executive director for the Washington State affiliate to the National Organization on Fetal Alcohol Syndrome and the co-founder of the FAS Friends FASD Community Support Network. She conducts workshops and training sessions on fetal alcohol syndrome and effective advocacy.

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Maternal and Child Public Health Leadership Training Program

The Maternal and Child Public Health Leadership Training Program offers a two-year, in-residence interdisciplinary program that leads to a master in public health degree with a focus on maternal and child health. Students graduate from the program with the skills and competencies to become leaders in improving the systems, programs, and policies that support the health of children and families in the United States. The following students were admitted for the 2011 academic year:

David Avenetti has a doctorate in dental surgery from the University of California, Los Angeles. As the president of the local chapter of the American Student Dental Association, he travels throughout the country to discuss, lobby, and advocate for oral health. His interest is to provide dental care to underserved children. Ultimately, he hopes to provide pediatric dental care to children with special health care needs.

Libby Brockman earned a bachelor of science degree in both neuroscience and psychology from Brandeis University, Waltham, Mass. For the last several years, she has worked as a research assistant at the Center for Child Health, Behavior, and Development at the University of Washington. She is particularly interested in exploring the role of education in curbing risk behaviors in adolescents.

Lisa Callegari has a medical degree in obstetrics and gynecology from Harvard Medical School, Boston, Mass. She has been a clinician at Kaiser Permanente in northern California for the last several years and has a long history of interest in reproductive health research. Lisa looks forward to a career as an independent researcher conducting studies to improve reproductive outcomes.

Maria Campanaro earned a bachelor of science degree in health education from the University of Minnesota, Duluth. She spent several years working as a teacher's aide in an elementary school. Her most recent work has been as an education specialist with Planned Parenthood, supporting classroom learning. She is interested in curriculum development, child nutrition, and sexual health education.

Meggie Inouye is in the Pediatric Nurse Practitioner Program in the School of Nursing and is a trainee at the Pediatric Pulmonary Center, both at the University of Washington. Her primary goal is to work as a pediatric primary care provider in a community clinic and to develop, monitor, and evaluate health promotion and prevention programs for vulnerable populations.

Lauren Sterling earned a bachelor of science degree in both public health and microbiology from the University of Washington. She is currently the program coordinator for the Center for AIDS Research at the University of Washington. Her goal is to become a clinician researcher specializing in the care of women with HIV and sexually transmitted diseases.

Michael Young earned a bachelor of science degree in environmental sciences from the University of California, Berkeley. Michael has been involved in research analyzing the association between prenatal exposure to air pollution and birth weight. He looks forward to a career in environmental epidemiology and to producing research results that inform safe child birth policies.

Sarah Zelek earned a bachelor of arts degree in biology and society from Cornell University, Ithaca, New York. Currently, she works as an executive assistant in the Medical Services Department of Sea Mar Community Health Centers, where she analyzes quality improvement data, coordinates research initiatives, and supervises care coordinators. She is particularly interested in infant feeding practices, nutrition, and obesity, especially in marginalized populations.

State Reports . . .

Prevalence of Fetal Alcohol Syndrome Declines Among Alaska Native Infants

Alaska Department of Health
and Social Services

Yvonne Wu Goldsmith

In 1998 Alaska State established a [passive surveillance system](#) to track infants with an ICD9 code of 760.71 (infant affected by prenatal alcohol exposure). Physicians and hospitals and other health care entities must report this condition for children, through five years of age, to the Alaska Birth Defects Registry. The project coordinator for the registry is responsible for collecting medical information and determining if a child meets the [case definition for fetal alcohol syndrome \(FAS\)](#).

The Alaska Birth Defects Registry uses a definition developed by the Centers for Disease Control and Prevention FAS Surveillance Network. A FAS case must have medical chart documentation of each of the following:

- ◆ At least two fetal alcohol syndrome facial feature characteristics or comment of "facial features consistent with FAS"
- ◆ Growth deficiency
- ◆ Central nervous system impairment

During 1996-2002, the prevalence of FAS in Alaska decreased from 19.9 to 13.5 per 10,000 live births. This decline was limited entirely to Alaska Native children who experienced a 49% decline, from 63.1 to 32.4 per 10,000 live births. The prevalence of FAS among non-Native children increased 64%, from 3.7 to 6.1 per 10,000 live births. The prevalence ratio of Alaska Native to non-Native infants fell from 17 in 1996-1998 to 5 in 2000-2002.

Prevention Activities

The observed decline in the prevalence of FAS among Alaska Native infants occurred in association with a number of prevention activities: development and sustainability of a network of community-based fetal alcohol spectrum disorders (FASD) diagnostic teams, development of university-level FASD curricula and

statewide training programs for educators and providers, a statewide multi-media public awareness campaign, and increased substance use screening in primary care settings. It is unclear why the prevalence of FAS has not declined among non-Native children.

There are limitations to the data. Only children reported to the registry and whose records have been reviewed by a medical abstractor are counted. Heightened awareness of maternal alcohol use among Alaska Natives and a well-established system for referral and diagnosis of FAS may result in more complete reporting for Alaska Natives as compared with non-Natives. Rates may be underestimated for non-Natives as a result of possible underreporting.

Health care providers should familiarize themselves with signs of alcohol abuse and provide patient education and appropriate referrals for pregnant women and women of childbearing age. ❖

Yvonne Goldsmith, MS, tracks health indicators and engages in research on maternal, child, and family health for the Alaska Department of Health and Social Services, Division of Public Health. She also serves on the editorial board of the Northwest Bulletin: Family and Child Health.

Resources

Alaska Dept. of Health and Social Services, Division of Public Health. Decline in the Birth Prevalence of Fetal Alcohol Syndrome in Alaska. Epi Bulletin No. 3, February 17, 2010. www.epi.hss.state.ak.us/bulletins/docs/b2010_03.pdf

Alaska Dept. of Health and Social Services, Division of Public Health. Alaska Birth Defects Monitor. Vol III, Issue 2, July 2010. www.hss.state.ak.us/publications/ABDRnewslettersV3-2July23-10.pdf

Alcohol Use During Pregnancy: Results from the 2006 PRATS

Idaho Department
of Health and Welfare

Jacquie Daniel

No amount of alcohol during pregnancy is considered safe. Therefore, it is recommended that pregnant women and women who may become pregnant abstain from alcohol.⁽¹⁾ In Idaho State, the majority (88.9%) of women did not drink during pregnancy; however, 40.6% of women drank before pregnancy and 3.4% drank during the last three months of pregnancy. Less than one alcoholic beverage per week was the most common reported amount consumed among women who drank during pregnancy. The least common reported amount was four to six drinks per week, with no reports of seven or more drinks per week.

These data are from the 2006 Pregnancy Risk Assessment Tracking System (PRATS), a population-based tracking system that surveys new mothers in the state about their behaviors and experiences before and during pregnancy. Rates of drinking have not changed significantly over the previous five years.

The 2006 survey included the following questions about alcohol use: “Have you had any alcoholic drinks in the past two years?” If mothers answered “Yes,” they were asked:

- ◆ “During the three months before you got pregnant, how many alcoholic drinks did you have in an average week?”
- ◆ “During the last three months of your pregnancy, how many alcoholic drinks did you have in an average week?”

Prenatal Care Discussion

Also included in the survey are questions about prenatal care. Almost eight-in-ten women (79.1%) reported that their prenatal care provider had asked them if they were drinking alcohol during pregnancy. Nearly nine-in-ten women (88.3%) reported that their health care provider informed them of how alcohol consumption could affect their baby. There were no

significant difference between mothers who drank during pregnancy and mothers who did not drink during pregnancy in having these discussions with their health care provider.

Rates of Drinking During Pregnancy

In general, older and more educated mothers were more likely to drink during pregnancy, while younger and less educated mothers were more likely to smoke during pregnancy. Drinking during pregnancy was nearly four times as prevalent in mothers age 35 or older compared with younger mothers (9.6% versus 2.7%). Mothers with a bachelor’s degree or higher were twice as likely to drink during pregnancy compared with less educated mother (5.5% versus 2.7%).

The same trend was found in household income, with mothers with higher incomes more likely to drink during pregnancy and mothers with lower incomes more likely to smoke during pregnancy. Drinking was three times more prevalent among mothers whose households made \$50,000 or greater per year compared with mothers whose households had lower incomes (6.8% versus 2.2%). ❖

Jacquie Daniel manages the Children’s Special Health Program at the Idaho Department of Health and Welfare and is the Title V Children with Special Health Care Needs director for Idaho State. Prior to this, she managed the Idaho Pregnancy Risk Assessment Tracking System (PRATS), a significant source of maternal and perinatal data for the state.

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References

1. Office of the Surgeon General. Surgeon General’s Advisory on Alcohol Use in Pregnancy. US Department of Health and Human Services. 2005.

Decreasing the Risk of a Lifetime Dependence on Alcohol

Oregon Department
of Human Services

Lesla Dixon-Gray

Title V programs are committed to addressing those issues considered most urgent and challenging to the overall health of rural and urban communities. Oregon State's 2011 Title V Maternal and Child Health Needs Assessment identified alcohol and other drug use by pregnant women, parents of young children, adolescents, and young adults as an urgent issue. Never before in the period of conducting a needs assessment has alcohol use been identified as a priority. Data from the 2009 Oregon Healthy Teens Survey indicate that:

- ◆ 80% of 11th-grade students who have drunk alcohol report first use at age 14 years or younger
- ◆ 8.7% of Oregon women report consuming some alcohol in last three months of pregnancy

Comparable national data (PRAMS 2007) are:

- ◆ 6.3% of women report consuming some alcohol in the last three months of pregnancy
- ◆ 1.6% of women report receiving help with an alcohol or drug problem during pregnancy

An association between age at first use of alcohol and lifetime dependence has been clearly established (see editorial by Lauri Turkovsky). In order to reduce this risk, Oregon State will focus on alcohol and other drug use by adolescents. The goal is to "decrease the percent of 11th-grade students who were 14 years old or younger when they had more than a sip or two of beer, wine, or hard liquor for the first time."

Next Steps

The Oregon Office of Family Health has developed objectives and activities to address this state priority in collaboration with other state offices and programs, university health centers, and local county public health departments. Future activities will include

offering technical assistance to local county public health departments regarding substance-exposed pregnancies and under-age alcohol use, provider screening, and binge drinking.

In addition, a statewide environmental inventory of current alcohol prevention programs, policies, and activities is planned. Information will be used in strategic planning and development of an alcohol and drug policy database. These activities will allow state family health officers to understand the range of policies in place, identify gaps, and encourage state and local partners to strengthen their alcohol and drug prevention policies, programs, and activities over the next four years. ❖

Lesla Dixon-Gray, MSW, MPH, has worked in maternal and child health for over 10 years. She is the women's health program coordinator for the Maternal and Child Health Section, Office of Family Health, Oregon Public Health.

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Resources

For more information on alcohol use by women in Oregon, go to <http://public.health.oregon.gov/DiseasesConditions/CommunicableDisease/CDSummaryNewsletter/Documents/2007/ohd5619.pdf>

For information on alcohol use by youth, go to <http://public.health.oregon.gov/DiseasesConditions/CommunicableDisease/CDSummaryNewsletter/Documents/2003/ohd5208.pdf>

An upcoming issue of *CD Summary* will cover the topic of early initiation of alcohol use and lifetime dependence. For more information, go to <http://public.health.oregon.gov/DiseasesConditions/CommunicableDisease/CDSummaryNewsletter/Pages/cdsum.aspx>

Four Decades of a Successful Approach to FASD Prevention

Washington State
Department of Health

Susan Astley

Washington State has led the world in strategies to reduce the incidence of fetal alcohol spectrum disorders (FASD) and to identify and support affected children and adults. The negative impact of alcohol on the developing fetus was first noted at the University of Washington, Seattle, in 1968. This led to the creation of two large programs: The Fetal Alcohol Syndrome (FAS) Diagnostic and Prevention Network and the Fetal Alcohol and Drug Unit.

The mission of the FAS Diagnostic and Prevention Network (www.fasdpn.org) is to:

- ◆ Provide diagnostic and treatment referral services to individuals of all ages with prenatal alcohol exposure through a statewide network of interdisciplinary [FASD diagnostic clinics](#)
- ◆ Design and implement evidence-based intervention services for children and families impacted by FASD ([Families Moving Forward Program](#))
- ◆ Conduct FAS [screening and surveillance](#) of high-risk populations
- ◆ Identify and refer high-risk women to [primary prevention](#) and intervention programs
- ◆ Provide FASD [training](#) and education to professionals worldwide
- ◆ Create and distribute FASD screening, diagnostic, and surveillance [tools](#)
- ◆ Conduct [research](#) that will advance FASD diagnostic, intervention, and prevention efforts

The mission of Fetal Alcohol and Drug Unit (<http://depts.washington.edu/fadu/>) is to:

- ◆ Prevent FASD through its highly effective [Parent-Child Assistance Program](#)
- ◆ Provide FASD training worldwide
- ◆ Conduct research to identify the effects of prenatal alcohol and drug exposure across the life span

In 1995, Substitute [Senate Bill 5688](#) directed the establishment of the Washington State FAS Interagency Work Group to ensure the coordination of all programs serving individuals with FASD and women at high risk of having children with FASD. The mission of the Washington State FAS Interagency Work Group (www.fasdwa.org) is to:

- ◆ Increase awareness of FASD
- ◆ Expand capacity to identify and intervene with high-risk women
- ◆ Expand capacity to screen and diagnose FASD in high-risk individuals
- ◆ Improve service delivery to individuals and families affected by FASD
- ◆ Promote public policy for FASD prevention

The [comprehensive approach](#) to FASD prevention taken by Washington State over the past four decades has truly paid off. A 2004, Washington State [population-based surveillance study](#) documented a significant decline in maternal drinking during pregnancy correlated with a significant reduction in the prevalence of FAS. ❖

Susan Astley, PhD is a professor of epidemiology and pediatrics at the University of Washington, Seattle, and is the director of the FAS Diagnostic and Prevention Network. She has devoted the past 30 years to the diagnosis, intervention, and prevention of FASD.

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Percent of youth who drank at least one drink of alcohol during the past 30 days by grade and state. Data from the states of Alaska and Idaho are from the 2009 Youth Risk Behavior Surveillance System (YRBSS). Data from Oregon State are from the 2009 Oregon Healthy Teens Survey. Data from Washington State are from the 2010 Healthy Youth Survey.

	8th Grade		9th Grade		10th Grade		11th Grade	
	Female	Male	Female	Male	Female	Male	Female	Male
- - - Percent - - -								
Alaska	NA	NA	25.5	20.2	32.9	32.1	35.8	36.4
Idaho	NA	NA	29.9	29.4	36.4	31.2	32.3	37.0
Oregon	24.2	22.1	NA	NA	NA	NA	39.9	36.6
Washington	15.6	13.1	NA	NA	29.1	26.1	NA	NA

On-Line Training Opportunity. . .

What We’ve Learned and Challenges We Face in Preventing Fetal Alcohol Spectrum Disorders

This **webinar** provides an overview of the teratogenic effects of prenatal alcohol exposure and the adverse long-term consequences of fetal alcohol spectrum disorders. Topics include:

- ◆ Trends in rates of drinking during pregnancy in Washington State
- ◆ Ongoing challenges related to alcohol abuse faced by public health and medical providers
- ◆ The role providers play in preventing fetal alcohol spectrum disorders

Presenter: Therese Grant, PhD, is an epidemiologist who has worked in maternal substance abuse research, prevention, and intervention for over 20 years. She is a member of the University of Washington School of Medicine faculty, where she is the Ann Streissguth Endowed Professor in Fetal Alcohol Spectrum Disorders and director of the Fetal Alcohol and Drug Unit.

Since 1991 she has directed the University of Washington [Parent-Child Assistance Program](#), an evidence-based prevention and intervention program working with women at high-risk for abusing alcohol and drugs and their families. Sites are located in nine Washington State counties and at over two dozen other locations in the United States and Canada.

This webinar is part of a series of webinars sponsored by the Maternal and Child Public Health Leadership Training Program with a grant from the Maternal and Child Health Bureau. To view previous webinars, go to <http://www.nwcphp.org/training/courses/maternal-child-health-mch-training-for-professionals>

When: Friday, October 28th, at noon (Pacific Time)
To register: shattuck@u.washington.edu

Resources . . .

Alcohol: A Woman's Health Issue

National Institute on Alcohol Abuse and Alcoholism
<http://pubs.niaaa.nih.gov/publications/brochure-women/women.htm#research>

Alcohol and Drug Abuse Institute, University of Washington. A comprehensive resource including "drug use epidemiology" page with specific links to local data. <http://depts.washington.edu/adai/>

Crowe-Salazar N. *Substance Use During Pregnancy and a Women Centred Harm Reduction Approach: Challenging the Mother and Baby Divide to Support Family Well-Being*. Unpublished paper; 2009. www.whitebearfirstnation.ca/Substance%20Use%20during%20Pregnancy%20and%20a%20Women%20Centered%20Harm%20Reduction%20Approach.pdf

Emory University Maternal Substance Abuse and Child Development
www.psychiatry.emory.edu/PROGRAMS/GA-Drug/

Iceberg Newsletter

Information about Fetal Alcohol Spectrum Disorders from 1991-2010. No longer updated.
www.fasiceberg.org/index.htm

Mothering and Substance Use: Approaches to Prevention, Harm Reduction, and Treatment. Vancouver, British Columbia: British Columbia Centre of Excellence for Women's Health; 2010.
www.bcccewh.bc.ca/publications-resources/documents/GenderingNatFrameworkMotheringand-SubstanceUse.pdf

The National Center on Addiction and Substance Abuse at Columbia University
www.casacolumbia.org/templates/Home.aspx?articleid=287&zoneid=32

National Institute on Alcohol Abuse and Alcoholism National Institutes of Health
News, resources, research, and data about alcohol consumption, prevention, and treatment for professionals and families
www.niaaa.nih.gov

National Institute on Drug Abuse

Program information and publications about the health aspects of drug abuse and addiction to inform policy and improve practice. Includes drug-use screening tools, publications about co-occurring drug abuse and mental illness, research

summaries about prevention and treatment, and statistics about drug use.

www.drugabuse.gov/nidahome

Native American Center for Excellence Substance Abuse and Mental Health Services Administration
<http://nace.samhsa.gov/index.aspx>

Northwest Frontier Addiction Transfer Center Network, Oregon Health and Science University. Information targeting the treatment provider community however excellent information and links.
www.nattc.org/regcenters/index_northwestfrontier.asp

Substance Abuse and Mental Health Services Administration
Multi-resource agency including publications, reports, evidence-based practice, program development, community capacity support, and research.
www.samhsa.gov/

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