Mary Marden Velasquez
Karen S. Ingersoll
Mark B. Sobell
Linda Carter Sobell

Advances in Psychotherapy –
Evidence-Based Practice

Women and Drinking: Preventing Alcohol-Exposed Pregnancies

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Women and Drinking

About the Authors

Dr. Mary Velasquez is Centennial Professor in Leadership for Community, Corporate, and Professional Excellence and director of the Health Behavior Research and Training Program at the University of Texas at Austin. Her research focuses on the development and testing of behavioral interventions in healthcare settings, screening and brief interventions, group treatment for substance use, and preventing fetal alcohol spectrum disorder.

Dr. Karen Ingersoll is associate professor of Psychiatry and Neurobehavioral Sciences at the University of Virginia School of Medicine, Charlottesville, VA. Dr. Ingersoll's focus is the intersection of addiction and health. She has developed and tested motivational interventions that target health behaviors and addictive behaviors together for two decades, including multiple studies of interventions to reduce the risk of alcohol-exposed pregnancy.

Drs. Linda and Mark Sobell are both professors at Nova Southeastern University, Ft. Lauderdale, FL, and have had a clinical research career spanning four decades. They are nationally and internationally known for their research in the addictions field, including the development of the Timeline Followback and Guided Self-Change model of treatment. They both have received several awards including the Jellinek Memorial Award for outstanding contributions to knowledge in the field of alcohol studies.

Advances in Psychotherapy – Evidence-Based Practice

The basic objective of this series is to provide therapists with practical, evidence-based treatment guidance for the most common disorders seen in clinical practice – and to do so in a reader-friendly manner. Each book in the series is both a compact "how-to" reference on a particular disorder for use by professional clinicians in their daily work and an ideal educational resource for students as well as for practice-oriented continuing education.

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Women and Drinking

Preventing Alcohol-Exposed Pregnancies

Mary Marden Velasquez
Health Behavior Research and Training Institute, University of Texas at Austin, TX

Karen S. Ingersoll
University of Virginia School of Medicine, Charlottesville, VA

Mark B. Sobell and Linda Carter Sobell
Center for Psychological Studies, Nova Southeastern University, Fort Lauderdale, FL

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Preface

This book is written to help psychologists and other health care providers identify and make referrals for women who might be at risk of an alcohol-exposed pregnancy (AEP), and to describe evidence-based interventions that are designed to prevent AEPs.

The harmful effects of a women's drinking on her unborn child are not a new concern. Historically, while concerns about maternal drinking date back to biblical times, scientific investigations into fetal alcohol exposure were largely nonexistent through the early 1970s. In 1996, an Institute of Medicine (IOM) committee was charged with improving the understanding of available research knowledge and experience on approaches for diagnosing fetal alcohol syndrome (FAS) and related disorders as well as the prevalence of FAS and related disorders in the general population (Institute of Medicine, 1996). It was not until the IOM published its pivotal paper discussing issues related to the prevalence, diagnosis, treatment, and prevention of FAS, that we started to learn the extent of the full spectrum of fetal alcohol spectrum disorder (FASD). For example, we learned that fetal alcohol exposure was the leading known cause of intellectual disability in the Western world and, importantly, that FASD is a 100% preventable disability.

We also learned that drinking during pregnancy can cause birth defects; mild to severe intellectual disabilities; mental health problems; and emotional, learning, and behavioral problems called FASD (O'Connor & Paley, 2009; Streissguth et al., 2004). The most severe of these disorders, FAS, is associated with a combination of abnormal facial features, neurodevelopmental disorders, growth deficits, and overall poor outcomes. FASDs, including FAS, are a significant challenge for the scientific community and the health care system (Bertrand et al., 2004). Alcohol consumption among pregnant women is a significant public health concern, and preventing AEPs has been identified as a health care priority by several major and influential groups. Recommendations against drinking during pregnancy have been published by the IOM (Stratton, Howe, & Battaglia, 1996), the US Surgeon General's Office (Office of the Surgeon General, 2005), and the US Department of Health and Human Services, Office of Disease Prevention and Health Promotion (2011).

Although the best time to prevent AEPs is prior to conception, women – including those who intend to become pregnant – may not be aware that they have conceived until several weeks or months into their pregnancy. Consequently, during this key phase of fetal development, many women continue to drink. Further, half of all women of childbearing age drink alcohol, and nearly half of all pregnancies are unplanned. What we know today, and what is the focus of this book, is that a variety of brief motivational behavioral interventions developed for nonpregnant women of childbearing age can effectively prevent AEPs (Cannon et al., 2014). Health care practitioners from multiple disciplines (e.g., psychologists, physicians, social workers) are well suited to deliver these interventions because they are trained to target specific

behavioral change, and because women of childbearing age present to a wide variety of practitioners in different health care settings. The multiple evidence-based Changing High-Risk Alcohol Use and Improving Contraception Effectiveness Study (CHOICES) and CHOICES-like interventions, which are described in Chapter 3, all have been shown to reduce the risk of AEP across multiple practice settings, ranging from those where risk is high (e.g., jails, mental health and substance abuse treatment centers), to more "opportunistic" settings that serve significant numbers of women of childbearing age (e.g., primary care clinics, universities and colleges), to brochures that can be provided at no cost in the community (e.g., health care settings, pharmacies, physicians' offices).

The work described in this book is based on clinical trials from several FASD prevention studies that were funded by the US Centers for Disease Control and Prevention (CDC) to reduce the incidence of AEP. These multisite research and dissemination efforts started with a program of research known as Project CHOICES, which had several objectives. The first was to identify community settings where women would be at a high risk for an AEP (Project CHOICES Research Group, 2002). The second objective was to develop, test, and refine a comprehensive behavioral program to reach women who were at risk of an AEP (Project CHOICES Intervention Research Group, 2003). An initial multisite randomized controlled trial (RCT), conducted from 2002 to 2005, demonstrated that the CHOICES intervention could reduce risks for an AEP, preventing the harmful effects of FAS and FASD (Floyd et al., 2007). The CHOICES efficacy study was awarded the 2008 Charles C. Shepard Science Award at the CDC for excellence in prevention and control.

The multisite CHOICES team consisted of several principal investigators including the four authors of this book along with Drs. R. Louise Floyd, Patricia Dolan Mullen, Mary Nettleman, Kirk von Sternberg, and Kenneth Johnson. Following the initial studies, and over the course of 15 years, several of the investigators have conducted a series of additional RCTs, with each successive study informing the next. These studies and their results are described in Chapter 3. The successful outcomes for the six CHOICES and the CHOICES-like studies are shown individually in the first six tables in Chapter 3. To better reflect the overall impact of the success of the six CHOICES and CHOICES like studies, a final table in Chapter 3 lists the percentage of women in the six studies who met criteria for an overall reduced risk of an AEP at 6 months postintervention for the CHOICES (experimental group) compared with a Standard FASD intervention group (control). Remembering that *all* women in this table, control or experimental, were at risk when they entered the studies, the percentages for reduced risk for a postintervention AEP even for the control groups are impressive. However, the percentage of change is higher in the CHOICES or CHOICES-like studies. These research studies were all conducted in very different settings (e.g., primary care, university-hospital based obstetrical/gynecology practices, urban jails, substance abuse treatment settings, Native American tribal settings, primary care medical settings, media-recruited samples), and they included both college students and nonstudent groups.

We "Four Musketeers" (as we have come to call ourselves over the years) encourage you to use the information and intervention strategies presented

in this book in ways that best suit your practice and setting. Whether or not this intervention fits within your particular program or treatment context, we urge you to increase your knowledge about AEP prevention and to share this knowledge with your colleagues who may be unaware of the effects of alcohol on pregnancy. The impact of preventing just one pregnancy affected by alcohol is significant – preventing just one child from the effects of FAS could mean saving more than US $2 million across a person's lifetime, as well as avoiding the challenges that the children and their families face when dealing with FASD and the impact on the quality of their lives. We hope this book will be a valuable guide in helping you reduce the risk of AEP in the women you serve and in the communities in which you work.

Acknowledgments

We are indebted to our research teams and our families who supported us as we conducted the many years of research and writing that are reflected in this work. We want to thank Danny Wedding for his guidance (and patience) as we worked our way through a project that turned out to be much bigger and to take much longer than we originally anticipated.

The development of the CHOICES intervention was made possible by the invaluable contributions of the other Principal Investigators, Drs. Mary Nettleman, Pat Mullen, and Kenneth Johnson. We also greatly appreciate the assistance of Dr. Kirk von Sternberg, Dr. Nanette Stephens, Dr. Beth Pomeroy, Shannon Johnson, Kyle Pitzer, and Sophia Sarantakos who helped in the completion of this book. We thank Janet Sharkis and Leah Davies from the Texas Office for the Prevention of Developmental Disabilities for their unwavering support and advocacy in FASD prevention. Likewise, we appreciate the assistance of the staff members at the US Centers for Disease Control and Prevention (CDC) who provided us valuable assistance in the preparation of the book.

Finally, we offer our sincere thanks to our colleagues at the CDC's National Center on Birth Defects and Developmental Disabilities who guided many of the FASD prevention research and dissemination studies described in this book. Special thanks to R. Louise Floyd (to whom this book is dedicated) who captained the CHOICES program of research at the CDC, and to Colleen Boyle who oversaw and supported those efforts. These two individuals have believed in us, trusted us, advocated for us, and supported us – both scientifically and personally – through the challenges and successes of 20 plus years of collaboration in preventing alcohol-exposed pregnancies.

Finally, as we were in the final stages of finishing this book, we learned that the CDC, on September 12, 2014, announced that since being released in July of 2011, approximately 8,000 sets of the CHOICES curriculum package have been requested and distributed throughout the United States and other countries. This is a huge testament to the utility of the CHOICES intervention.

Dedication

We dedicate this book to Dr. R. Louise Floyd who recognized that preventing alcohol-exposed pregnancy required a new approach. We acknowledge her instrumental leadership in this area and her ongoing commitment to preventing fetal alcohol spectrum disorders.

Mary Velasquez
Karen Ingersoll
Mark Sobell
Linda Sobell

Table of Contents

Preface v
Acknowledgments viii
Dedication ix

1 Description 1
1.1 What Are Fetal Alcohol Spectrum Disorders? 1
1.2 How Is FASD recognized? 1
1.3 The History of FASD 2
1.4 Definitions of FASD and Related Disorders 4
1.5 Cause of FASD 5
1.6 How Does Alcohol Affect a Developing Fetus? 6
1.7 Effects of FASD Across the Lifespan 7
1.8 Fetal Alcohol Syndrome 8
1.9 Epidemiology of FASD and Related Disorders 10
1.9.1 How Prevalent Is FASD? 10
1.9.2 Costs of FASD 12

2 Theories and Models of FASD 14
2.1 What Puts Women at Risk? 14
2.1.1 What Is an Alcohol-Exposed Pregnancy? 14
2.1.2 CDC Definition of an AEP 15
2.1.3 Guidelines of Project CHOICES 15
2.1.4 Women and Drinking 16
2.2 Who Is at Risk for an AEP? 20
2.3 Screening for At-Risk Drinking 22
2.3.1 Single Binge Drinking Question 22
2.3.2 Weekly Drinking ≥ 8 SDs as a Risk Factor for AEPs 22
2.3.3 Quick Drinking Screen 23
2.4 Screening for Ineffective Contraception 24
2.5 Summary: What Puts Women at Risk for an AEP? 25

3 Preventing Alcohol-Exposed Pregnancies 26
3.1 Prevention Dilemma 26
3.2 Primary Prevention Strategies 27
3.3 Evidence-Based Approaches for the Prevention of AEP 29
3.3.1 Project CHOICES 30
3.3.2 Project BALANCE 35
3.3.3 Project CHOICES and Healthy Moms 36
3.3.4 CHOICES Plus 37
3.3.5 Project EARLY 38
3.3.6 Project Healthy CHOICES 40
3.4 Secondary Prevention: Minimizing Alcohol-Related Harm During Pregnancy 43
3.5 Summary 45

4 Treatment: Dissemination Efforts for Avoiding Alcohol-Exposed Pregnancies 47
4.1 Knowledge About AEP and FASD Among Practitioners and the Public 47
4.2 Developing Programs for Preventing AEPs 48
4.3 Things Practitioners Can Do To Help Women Prevent an AEP . 49
4.4 Putting CHOICES Into Practice 49
4.4.1 CHOICES' Training Resources 50
4.4.2 Additional Training Considerations. 50
4.4.3 Cultural Adaptations of the CHOICES Intervention 51
4.4.4 Future Considerations 52
4.5 Impact of CHOICES Dissemination on Public Policy 53
4.6 CHOICES-Like Interventions in Colleges and Universities: An Easy, Effective, and Essential Dissemination Effort 54
4.7 Conclusion 55

5 Case Vignette 56

6 Further Reading 60

7 References 62

8 Appendix: Tools and Resources 70

1

Description

Although the harmful effects of drinking alcohol during pregnancy have been observed for centuries, only in the past few decades has the relationship between prenatal alcohol use and birth defects been demonstrated (Randall, 2001). The concept of fetal alcohol spectrum disorders (FASDs) is relatively new, yet there have been differing opinions about how to label this continuum of disorders. In this chapter, the history of FASD and diagnostic issues are discussed. In addition, the magnitude of the problem and its consequences for individuals, families, and society is presented. Although the book's focus is on the prevention of alcohol-exposed pregnancies (AEPs), this chapter will help practitioners better understand the concept of FASD, the individuals affected, and the types of preventive services available for such individuals.

1.1 What Are Fetal Alcohol Spectrum Disorders?

FASD describes a range of effects in children related to maternal drinking during pregnancy

The term *fetal alcohol spectrum disorders* is not a clinical diagnosis; rather, it is an umbrella term that has been used to describe a range of effects in children whose mothers have consumed alcohol when pregnant (Riley, Infante, & Warren, 2011). This includes a range of physical, mental, behavioral, and/or learning disabilities related to alcohol exposure during gestation. The lifelong implications of FASD can include deficits in intellectual processes (e.g., problem solving, attention, learning, memory, visuospatial abilities, motor functioning, social skills). Often those diagnosed with FASD experience a number of mental health issues and have overall poor life functioning and negative outcomes (O'Connor & Paley, 2009; Streissguth et al., 2004). Fetal alcohol syndrome (FAS) is a condition that falls at the extreme end of the FASD continuum, and is associated with the most severe impairments in functioning.

1.2 How Is FASD recognized?

Because our understanding of the effects of maternal drinking during pregnancy is evolving, the development of diagnostic criteria to identify FASD is relatively new. A diagnostic schema recognizing the physical effects (e.g., abnormal facial features, growth problems, central nervous system problems), which can be more directly observed and are characteristic of FAS, was first issued by the Institute of Medicine (IOM; Stratton, Howe & Battaglia, 1996).

While the current *International Classification of Diseases* (ICD-10; World Health Organization, 2011) recognizes FAS, it does not recognize FASD, which contains a wider range of significant neurodevelopmental and mental health symptoms often associated with prenatal alcohol exposure (Bertrand & Dang, 2012).

Clinical Pearl
FASD Is a SPECTRUM of Disorders

FAS is a condition that falls at the extreme end of the FASD continuum, and it is associated with the most severe impairments in functioning

Conventional understandings of the impact of drinking during pregnancy were based on conceptualizations of fetal alcohol syndrome (FAS), a condition that is often easily detected by hallmark facial abnormalities. Although FAS is the most severe diagnosis under the fetal alcohol spectrum disorder (FASD) umbrella, multiple and varied disabilities and symptoms can arise from prenatal exposure to alcohol, and we urge practitioners to avoid the conventional view based on FAS and recognize that FASD refers to a broad spectrum of disorders from mild to severe. To do otherwise will only perpetuate problems in screening and diagnosis. We encourage practitioners to develop a thorough understanding of the effects of AEP, and to modify their practices accordingly. For instance, many of the symptoms falling under the central nervous system dysfunction cluster (e.g., hyperactivity, impulsivity, attention deficits, learning and intellectual disabilities) are not accompanied by facial abnormalities, and cannot be physically measured like growth deficiencies. To provide needed services to the children and families affected by FASD, practitioners need to recognize the more subtle signs of FASD.

1.3 The History of FASD

Concerns about the dangers of drinking during pregnancy have a long history, dating back to the medical literature in the 1700s

The physical effects of drinking during pregnancy were noted dating back as far as the 1700s when the Royal College of Physicians of London reported that babies born to mothers who drank heavily during pregnancy were "weak, feeble, and distempered" (Royal College of Physicians of London, 1726, p. 253). A related concern was depicted in a 1751 lithograph, *Gin Lane,* which English artist William Hogarth produced during London's so-called gin epidemic. Hogarth's print, which includes an image of a drunken woman letting a child fall from her arms, is a social commentary about the rampant use of highly distilled alcohol at the time, especially among women. When Hogarth published his print, fetal and infant death rates were higher than in previous years, even though it was a period of good wages, plentiful food, and relative freedom from the epidemic diseases that typically accounted for high infant mortality (Warren & Bast, 1988).

Reports of alcohol's negative effects on children continued throughout the 18th and 19th centuries. The earliest description of what is meant by the term *fetal alcohol syndrome* came from Dr. William Sullivan, a deputy medical officer at a prison in England. Sullivan observed that pregnant women prisoners who were heavy drinkers not only had higher rates of miscarriages but also that the babies who survived often displayed distinctive patterns of birth defects (Sullivan, 1899). Dr. Sullivan also reported that mortality and stillborn rates for children born to alcoholic mothers were more than twice those of

nonalcoholic mothers, and the more a woman drank during pregnancy, the greater the likelihood of fetal problems. During the anti-alcohol period of the 1920s and the onset of Prohibition in the United States, interest in FAS declined (Randall, 2001; Warren & Bast, 1988). Forty years later, in the early 1960s, interest in FAS gained some momentum with the publication of a few scientific articles. However, during this same period, many researchers tried to refute the idea that alcohol could be detrimental to an unborn baby (Warren & Bast, 1988).

Scientific interest in the effects of alcohol on birth outcomes and child development gained momentum in 1967 when a family physician, Alexandre LeMache, published a report in the French Academy of Medicine about his 37 years of work with more than 1,200 children born to alcoholic mothers (Warren & Bast, 1988). His observations included neurological and behavioral problems, mental retardation, genital malformations, facial anomalies, and a high infant death rate. Unfortunately, LeMache's report had a limited impact as it did not present diagnostic criteria that could have facilitated the identification of fetal alcohol effects (Hoyme et al., 2005). A subsequent French publication by Lemoine and his colleagues described anomalies in the children of parents with serious alcohol problems (Lemoine, Harousseau, Borteyni, & Menuet, 1968). This article also failed to receive much attention, perhaps because it was in French and because the journal had limited circulation. Several years later, a team of US researchers at the University of Washington, which included pediatric dysmorphologists and psychologists, reported patterns similar to those described by Lemoine.

Jones and Smith (1973) were the first to use the term *fetal alcohol syndrome* (FAS), describing it as "a diagnosis for two"

In 1973, a landmark study published in *The Lancet* described a small group of children all born to mothers who drank heavily during pregnancy (Jones, Smith, Ulleland, & Streissguth, 1973). All of the children had similar facial characteristics, growth deficiencies, and central nervous system dysfunction. In another publication that same year, Jones and Smith (1973) were the first to use the term *fetal alcohol syndrome* (FAS), describing it as "a diagnosis for two" (i.e., the child and the mother). Following this, there was a flurry of research studies, mostly epidemiological in nature.

From the 1970s on, epidemiological and case studies confirmed Jones and Smith's findings that maternal prenatal alcohol exposure can cause a pattern of permanent deficits in unborn children. By 1990, FAS had been documented in studies published in over 20 different languages (Abel, 1990). With sponsorship from the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the first international meeting on FAS was held in Seattle, Washington, in 1980.

During the 1980s and 1990s, professionals and practitioners became increasingly aware of the problems caused by AEPs. As it became clear that a range of developmental problems were associated with maternal alcohol consumption, and that children with distinctive FAS facial features represented only the severe end of this spectrum, it was also clear that concern about maternal drinking during pregnancies should not be limited to those women who drink heavily (Calhoun, 2011). Shortly before his death, Smith made a plea for the field to recognize a wider spectrum of damage caused by prenatal drinking which he termed *fetal alcohol effects* (Smith, 1981). This term, which was later used to describe intellectual disabilities and behavioral problems resulting from an AEP, has today fallen out of favor. In 1981, the

US Surgeon General's Office first recommended warnings against alcohol use during pregnancy (Office of the Surgeon General, 1981), and in 1988, the US Congress passed legislation requiring that alcoholic beverages carry warnings stating that pregnant women should not drink alcohol. In 2005, this advisory was updated, warning women that the risk of a baby being born with any of the FAS conditions increases with the amount of alcohol a pregnant woman consumes, as does the severity of the condition (Office of the Surgeon General, 2005). The Surgeon General's advisory is shown in the text box.

Surgeon General's FAS Advisory of 2005

The discovery of FAS led to considerable public education and awareness initiatives informing women to limit the amount of alcohol they consume while pregnant. However, since that time, more has been learned about the effects of alcohol on a fetus. It is now clear that no amount of alcohol can be considered safe.

I now wish to emphasize to prospective parents, health care practitioners, and all childbearing-aged women, especially those who are pregnant, the importance of not drinking alcohol if a woman is pregnant or considering becoming pregnant.

Based on the current, best science available we now know the following:

Alcohol consumed during pregnancy increases the risk of alcohol-related birth defects, including growth deficiencies, facial abnormalities, central nervous system impairment, behavioral disorders, and impaired intellectual development. No amount of alcohol consumption can be considered safe during pregnancy. Alcohol can damage a fetus at any stage of pregnancy. Damage can occur in the earliest weeks of pregnancy, even before a woman knows that she is pregnant. The cognitive deficits and behavioral problems resulting from prenatal alcohol exposure are permanent. Alcohol-related birth defects are completely preventable.

For these reasons:

- A pregnant woman should not drink alcohol during pregnancy.
- A pregnant woman who has already consumed alcohol during her pregnancy should stop in order to minimize further risk.
- A woman who is considering becoming pregnant should abstain from alcohol.

Recognizing that nearly half of all births in the United States are unplanned, women of childbearing age should consult their physician and take steps to reduce the possibility of prenatal alcohol exposure.

Health professionals should inquire routinely about alcohol consumption by women of childbearing age, inform them of the risks of alcohol consumption during pregnancy, and advise them not to drink alcoholic beverages during pregnancy.

From Office of the Surgeon General, US Department of Health and Human Services (2005). Retrieved from http://www.cdc.gov/ncbddd/fasd/documents/surgeongenbookmark.pdf

1.4 Definitions of FASD and Related Disorders

"When a pregnant woman drinks alcohol, so does her baby" (Office of the Surgeon General, 2005, p. 1)

Over the years there have been several different terms used to describe what is now called FASD. For example, fetal effects of an AEP have been categorized as alcohol-related neurodevelopmental disorder (ARND) involving mental and behavioral impairments (e.g., learning disabilities, poor school performance, poor impulse control, problems with memory, attention, and/or judgment), or

alcohol-related birth defects (ARBD) describing malformations of the skeletal system and major organ systems (e.g., defects of the heart, kidneys, bones, and/or auditory system). Other frequently used terms have been fetal alcohol effects (FAE; Smith, 1981) to describe the full range of disorders (Substance Abuse and Mental Health Services Administration [SAMHSA], 2009), and partial FAS (Institute of Medicine, 1996) for children who have some facial features of FAS and some growth retardation, neurodevelopmental problems, or behavior or cognitive abnormalities that cannot be explained by family background or environment alone.

Clinical Pearl
Commonly Used Terms

ARBD	Alcohol-related birth defects
ARND	Alcohol-related neurodevelopmental disorder
FAE	Fetal alcohol effects (term no longer used)
FAS	Fetal alcohol syndrome
FASD	Fetal alcohol spectrum disorder (Note: This is not a diagnostic term but an umbrella term that encompasses all disabilities caused by prenatal exposure to alcohol)
ND-PAE	Neurobehavioral disorder associated with prenatal alcohol exposure
pFAS	Partial fetal alcohol syndrome

In 2004, the National Organization on FASD (NOFAS) convened a task force to address the need to identify individuals with FASD and improve the delivery of services to individuals and their families. This group consisted of a broad range of experts (e.g., clinicians, researchers, parents, administrators) from several federal agencies (e.g., National Institutes of Health [NIH], CDC, SAMHSA). One of their major accomplishments was the development of specific guidelines for diagnosing FAS (Table 1).

1.5 Cause of FASD

There is no risk of a child suffering FASD if a woman does not drink when pregnant

The cause of FASD is clear: *any alcohol use during a woman's pregnancy*. If a woman does not drink alcohol when pregnant her baby cannot have FASD. When a woman does drink alcohol, the pattern and severity of problems caused by prenatal alcohol use depend on a number of factors including the timing, frequency, and quantity of alcohol exposure. It is still unclear why some women who drink alcohol when pregnant have babies with obvious damage, and others who drink similar amounts appear to have healthy babies with no discernible effects. Researchers are using animal models to investigate which factors (e.g., maternal nutrition, hormonal fluctuations) might alter the likelihood of alcohol exposure resulting in fetal damage (Caudill, 2010; Nguyen & Thomas, 2011). While some animal studies suggest that maternal nutritional deficiencies may contribute to the effects of alcohol during pregnancy, it does not necessarily follow that nutritional supplements would reduce the potential

for damage in humans. In the remainder of this chapter, the effects of alcohol on a developing fetus will be considered, followed by a discussion of the potential impact of this exposure across the lifespan.

1.6 How Does Alcohol Affect a Developing Fetus?

Risk of baby suffering an FAS condition increases with amount of alcohol a pregnant woman drinks, as does the risk for its severity

Alcohol can cause severe and permanent brain damage as early as third week of pregnancy when a developing embryo is only 0.5 mm in diameter

A *teratogen* is defined as any agent that can disrupt development of an embryo or fetus. Alcohol is a teratogen that crosses the placenta, and when a pregnant woman drinks, the alcohol consumed can affect the developing fetus. A woman's drinking during her pregnancy can have a profound impact on her unborn child at any time, particularly during the early weeks of gestation. Researchers have found that alcohol can cause severe and permanent brain damage as early as the third week of pregnancy when a developing embryo is only 0.5 mm in diameter, which is small enough to fit inside the zero on a penny (Collaborative Initiative on Fetal Alcohol Spectrum Disorders, 2012). The brain and central nervous system are also highly susceptible to the effects of prenatal alcohol. Some studies show that even light drinking during pregnancy can potentially place a child at risk for learning problems (e.g., slower reaction times, poor attention capabilities, lower intelligence; National Organization on Fetal Alcohol Syndrome [NOFAS] Colorado, 2013). Figure 1 shows alcohol exposure at different phases of embryo/fetal development and what part of the body it affects, with the darkest segments of each time line indicating the

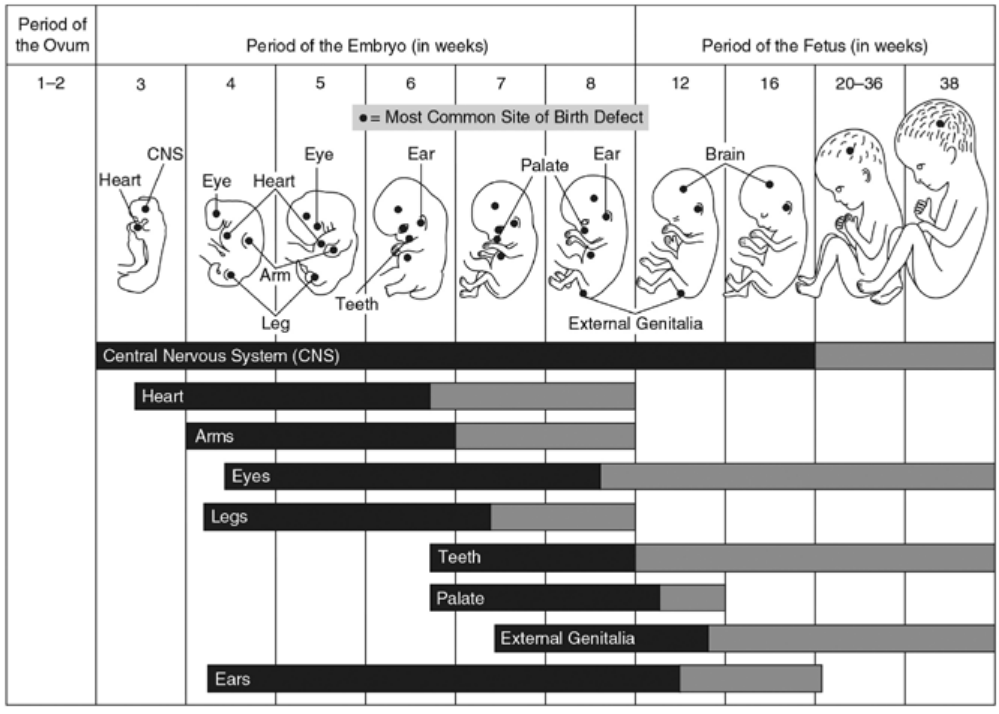

Figure 1
Alcohol exposure and phases of embryo/fetal development.
From National Institute on Alcohol Abuse and Alcoholism (2005). © NIAAA.

greatest sensitivity to alcohol. The lighter segments indicate periods of continued sensitivity to alcohol exposure during which physiological abnormalities and minor structural defects can still occur.

In some cases, FASDs (especially the disorders at the extreme end of the spectrum) are recognized at birth, especially when the mother's drinking history is known. In many cases, however, FASD is not identified until the child's problems become more apparent, and the negative effects of FASD are often first identified when a child experiences difficulties in school.

1.7 Effects of FASD Across the Lifespan

Individuals with FASD often grow up with social and emotional problems that cause them to encounter various difficulties as they move through the life cycle (e.g., mental illness, substance use disorders, difficulties in school or with the criminal justice system). As a person with FASD matures, the effects can be manifested in a variety of ways. The text box presents a list of characteristics often seen in people with FASD over different developmental periods.

Characteristics Often Seen in Individuals With FASD

Newborns or infants
- Sleep difficulties: unpredictable sleep/wake cycle
- Failure to thrive
- Feeding difficulties including weak sucking reflex
- Heart defects, kidney problems, or skeletal anomalies
- Easily overstimulated (increased sensitivity to light and sound)
- Neurological problems
- Poor fine motor control
- Poor gross motor control
- Seizures, tremors, or jitteriness
- Small size
- Susceptibility to infections

Preschoolers
- Small size
- Intellectual disabilities (mental retardation)
- Hyperactivity
- Lack of impulse control
- Emotional overreaction and tantrums
- Poor eye–hand and physical coordination
- Poor judgment (children are often overly friendly, being unable to recognize danger or have a healthy fear of strangers)
- Speech delays (slow vocabulary or grammar development, poor articulation, or perseverative speech)

Elementary school-aged children
- Poor impulse control
- Attention deficit disorders
- Hyperactivity
- Behavioral problems (acts such as lying, stealing, or defiance)

- Social difficulties (may include being overly friendly, immature, easily influenced by others, and difficulty with decision making)
- Language difficulties (delayed development, problems with expressive or receptive language)
- Learning disabilities or cognitive disabilities
- Memory difficulties
- Small size

Adolescents and young adults

- Low academic achievement
- Problems with abstract reasoning
- Poor judgment
- Difficulty in anticipating consequences
- Poor self-esteem
- Memory problems
- More pronounced impulsiveness (lying, stealing, or defiant acts)

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Original sources: CDC, 2014; FASCETS, 2010; National Organization on Fetal Alcohol Syndrome Colorado, 2013; Wattendorf & Muenke, 2005.

Because every individual is unique, not everyone will exhibit all of the characteristics related to FASD at any given age. When FASD is identified in infancy or early childhood, effective interventions can be put into place to help minimize negative consequences. Paley and O'Connor (2011) provide suggestions about effective behavioral strategies for working with children and adolescents with FASD. The US Substance Abuse and Mental Health Services Administration (SAMHSA) Treatment Improvement Protocol 58, titled *Addressing Fetal Alcohol Spectrum Disorders*, also provides information that can be used by practitioners to better identify patients in their practice who may have FASD. This publication also offers suggestions for referral, diagnosis, and intervention strategies for children, adolescents, and adults (SAMHSA, 2007).

1.8 Fetal Alcohol Syndrome

As mentioned earlier, FAS – the condition at the most extreme end of the FASD continuum – is the leading cause of intellectual disabilities in the United States. Diagnosing FAS can be difficult because there are no definitive tests (e.g., blood tests) or imaging technologies that can confirm a diagnosis. Over the years, the ability to diagnose FAS has been expanded and refined, but some controversy remains about which criteria to use. The various schemas all agree on the facial characteristics that characterize FAS, but they differ in how many other features or problems must be present for a definitive diagnosis. The most distinctive facial characteristics are (a) short palpebral fissures (i.e., the space between the margins of the eyelids), (b) a smooth philtrum (i.e., the vertical groove above the upper lip), and (c) a thin vermilion (i.e., the border of the

upper lip). Details on each of the diagnostic schemas can be found in the literature (Astley & Clarren, 2000; Bertrand et al., 2004; Chudley et al., 2005; Hoyme et al., 2005). Despite some differences, the schemas all rely on anomalies in three distinct areas: (a) prenatal and/or postnatal growth deficiency, (b) central nervous system (CNS) dysfunction, and (c) characteristic pattern of facial anomalies (Riley et al., 2011). The facial features are the easiest to recognize in children between the ages of 3 and 14 years. As children with FAS grow older, the facial features may change, making FAS more difficult to recognize. Figure 2 shows a drawing of the primary facial characteristics used in the diagnosis of FAS. Table 1 lists the guidelines for diagnosing FAS. These guidelines are intended to provide standard diagnostic criteria for FAS (Bertrand et al., 2004).

Table 1
Guidelines for Diagnosing Fetal Alcohol Syndrome

Abnormal facial features		Three distinct facial features: • Smooth ridge between the nose and upper lip • Thin upper lip • Short distance between the inner and outer corners of the eyes; wide-spaced appearance
Growth problems		Height and/or weight lower than normal (< 10th percentile)
Central nervous system problems	Structural	Differences in structure of the brain: • Smaller-than-normal head size • Significant changes in the structure of the brain
	Neurological	Problems with the nervous system: • Poor coordination • Poor muscle control • Problems with sucking as a baby
	Functional	Functions below what's expected for his or her age, schooling, or circumstances: • Cognitive deficits (e.g., low IQ) or Problems in at least three of the following areas: • Cognitive deficits or developmental delays • Executive functioning deficits • Motor functioning delays • Attention problems or hyperactivity • Problems with social skills • Other problems such as sensitivity to taste or touch, difficulty reading facial expression, and difficulty responding appropriately to common parenting practices

Adapted from Bertrand et al. (2004).

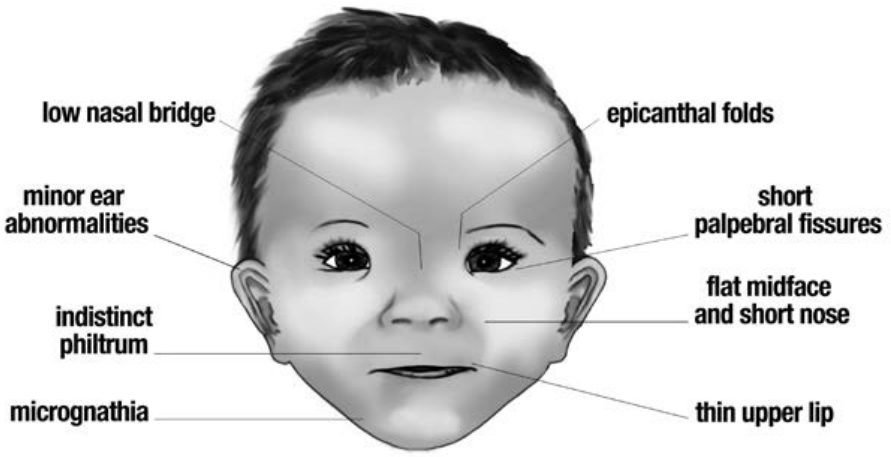

Figure 2
Fetal alcohol syndrome.
Reprinted with permision from Warren, K. R., Hewitt, B. G., & Thomas, J. D. (2010). Fetal alcohol spectrum disorders: Research challenges and opportunities. *Alcohol Research & Health: The Journal of the National Institute on Alcohol Abuse and Alcoholism, 34*(1), 5. © 2010 by the National Institute on Alcohol Abuse and Alcoholism.

1.9 Epidemiology of FASD and Related Disorders

1.9.1 How Prevalent Is FASD?

While there has been considerable progress over the last few decades in describing and identifying FASD, the prevalence of this disorder is still underestimated. Consequently, the full magnitude of the problem is unknown. Two other factors also contribute to the underestimation of FASD: (a) because most health care practitioners who work with children rarely screen for FASD, many children are not identified or counted in programs that monitor birth defects and developmental disabilities (Calhoun, 2011); and (b) there are wide variations in the identification of FASD, depending on the population sampled and the assessment method used. A review by May and colleagues (2009) estimated the prevalence of FASD in the United States to be at least 2 to 7 per 1,000 live births. However, in a more recent study using a middle class mainstream school population, May et al. (2014) found this estimate to be 24 to 48 per 1,000, substantially higher than general population estimates.

According to the CDC, of the approximately 4 million infants born each year in the United States, an estimated 1,000 to 6,000 will be born with FAS (CDC, 2004). The prevalence estimates for the entire FASD spectrum range are from 1% to 5%, with similar rates documented in other Western countries and even larger figures in countries with high rates of poverty (e.g., South Africa; Paley & O'Connor, 2011). Some children appear to be at even greater risk for FAS and FASD than others. For example, Native Americans in the United States have higher FAS rates compared with the US population in

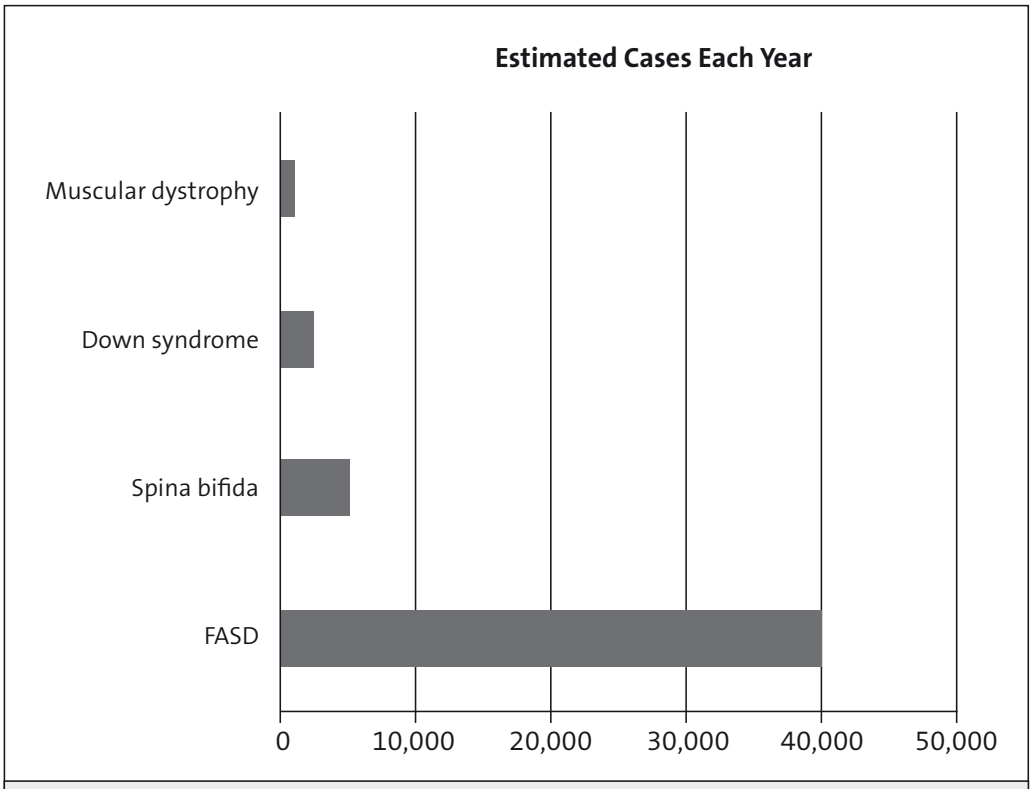

Figure 3
Estimates of fetal alcohol spectrum disorder (FASD) and other common childhood disabilities.
Reprinted with permission from National Organization on Fetal Alcohol Syndrome (NOFAS). (2014). *FASD: What everyone should know*. © 2014 by the National Organization on Fetal Alcohol Syndrome.

general. In a 2013 meta-analysis of 33 studies evaluating individuals across child-care systems (e.g., orphanages, foster care) in 12 countries, the pooled FAS prevalence and FASD prevalence rates were 6.0% and 16.9%, respectively (Lange, Shield, Rehm, & Popova, 2013). Figure 3 shows the number of estimated cases of FASD compared with other common developmental disabilities (e.g., Down syndrome, spina bifida).

Clinical Pearl
The Importance of FASD Prevention and Screening in High-Risk Community Settings

The prevalence of FASD appears to be higher in certain populations and particular settings. When conducting screening and prevention efforts with high-risk populations of women, we advise practitioners to remember that FASD addresses a spectrum of disorders from mild to severe. For example, FASD prevention efforts might especially benefit some Native American communities. Likewise, screening for FASD in foster care settings might bring help to children who require services. Finally, remember that women do not need to have an alcohol problem to be at risk of an AEP, as risky drinking relates to effects on an unborn child.

1.9.2 Costs of FASD

FASD is a major public health problem that affects individuals, families, and society (Riley et al., 2011). The emotional, physical, and social costs of this disability are lifelong and immense. No dollar amount can fully express the costs to individuals who are affected or their families. Families of individuals with FASD often are faced with (a) a scarcity of diagnostic and treatment services, (b) professionals who do not fully comprehend the nature of the disorder, and (c) lack of social support (Olson, Oti, Gelo, & Beck, 2009).

Individuals with FASD are known to be at greatly increased risk for a host of disabilities and problems with intellectual functioning and emotional regulation that may in turn contribute to many other difficulties (e.g., school failure, delinquency, substance use disorders; Alati et al., 2008; Streissguth et al., 2004). The text box, based on several scientific studies of individuals with FASD, shows the percentage of individuals with FASD who have other serious life problems.

Individuals With FASD Who Have Other Serious Life Problems

94% also have a mental illness

82% are unable to live independently

72% have experienced physical or sexual abuse, or domestic violence

60% have had disrupted school experiences

60% of those over the age of 12 have been charged with or convicted of a crime

45% have engaged in inappropriate sexual behavior

35% of adults and adolescents have been in prison for a crime

35% have alcohol and drug problems

Reprinted with permission from Texas Office for the Prevention of Developmental Disabilities. (2014). *Fetal alcohol spectrum disorder*, http://www.topdd.state.tx.us/fasd/. © 2014 Texas Office for the Prevention of Developmental Disabilities.
Source: Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. I. (1996). *Final report to the Centers for Disease Control and Prevention (CDC)* (Tech. Rep. No. 96-06). Seattle, WA: Fetal Alcohol & Drug Unit.

FASD is a lifelong condition, and its related problems differ as individuals develop over their lifespan. Dollar estimates of the cost of FASD vary, depending on the source and how they are calculated. The National Organization on Fetal Alcohol Syndrome (2013) estimates the lifetime cost of treatment for one individual with FAS to be US $1.4 million. The majority of these costs are for medical and mental health treatment and special education. When considering the full range of FASD problems, the annual costs in the United States are estimated at US $3.6 billion. Research in other countries reflects similarly high costs related for FASD (Stade et al., 2009; Thanh & Jonsson, 2009).

Although the effects of FASD cannot be reversed, with early diagnosis and adequate treatment and service provision, they can be accommodated

While the effects of FASD cannot be reversed, with early diagnosis and adequate treatment and service provision, these effects can be accommodated. This means that individuals with FASD can grow, improve, and learn to function better throughout their lives. The best way to help prevent FASD, however, is by teaching others, particularly women of reproductive age, about the