Fetal Alcohol Spectrum Disorders

Competency-Based
Curriculum Development Guide
for Medical and Allied Health Education and Practice

FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Introduction

Background

Maternal prenatal alcohol use is one of the leading preventable causes of birth defects and developmental disabilities. Children exposed to alcohol during fetal development can suffer a wide array of disorders, from subtle changes in IQ and behaviors to profound intellectual disability. These conditions are known as fetal alcohol spectrum disorders (FASDs). One of the most complex conditions within the spectrum is fetal alcohol syndrome (FAS), which involves disorders of the brain, growth retardation, and facial malformations (Stratton, Howe, & Battaglia, 1996; Secretary of Health and Human Services, 2000).

Health care professionals play a crucial role in identifying women at risk for an alcohol-exposed pregnancy and in identifying effects of prenatal alcohol exposure in individuals. However, despite the data regarding alcohol consumption among women of childbearing age and the prevalence of FAS, screening for alcohol use among female patients of childbearing age and diagnosis of FAS and related conditions are not yet common standards of care. In addition, it is known from surveys of multiple provider types that although they might be familiar with the etiology, teratology, and clinical presentation of FAS and FASDs, providers report feeling less prepared to identify and counsel women at risk for an alcohol-exposed pregnancy (e.g., obstetrician-gynecologists) or diagnose or identify for referral a child with FAS, and even less prepared to manage and coordinate the treatment of children with FASDs (e.g., pediatricians) (Anderson et al., 2010; Diekman et al., 2000; Gahagan et al., 2006). One of CDC's multifaceted initiatives in combating alcohol-exposed pregnancies is the education, training, and continuing education of medical and allied health students and practitioners.

In 1999, Congress directed the Secretary of the U.S. Department of Health and Human Services to convene the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, coordinated and managed by the FAS Prevention Team in CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD). The Task Force recommended several approaches to enhance FASD prevention, identification, and treatment efforts. One of these recommendations was the development of programs to educate health care professionals about prenatal alcohol–related disorders.

As part of the fiscal year 2002 appropriations legislation, Congress approved funding for CDC, acting through NCBDDD's FAS Prevention Team and in coordination with the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, other federally funded FAS programs, and appropriate nongovernmental organizations, to:

- Develop guidelines for diagnosing FAS and other negative birth outcomes resulting from prenatal exposure to alcohol.

- Incorporate these guidelines into curricula for medical and allied health students and practitioners, and seek to have these curricula fully recognized by professional organizations and accrediting boards.

- Disseminate curricula to and provide training for medical and allied health students and practitioners regarding these guidelines.

As part of CDC's response, a total of seven Fetal Alcohol Spectrum Disorders (FASD) Regional Training Centers (RTCs) were established. Through four three-year funding cycles, medical and allied health students and professionals have been trained in the prevention, identification, and treatment of FAS and related disorders, now known collectively as FASDs. From 2002 to 2014 the following RTCs were supported through one or more funding cycles:

- Arctic – based at University of Alaska Anchorage
- Frontier – based at University of Nevada, Reno
- Great Lakes – based at the University of Wisconsin
- Midwestern – based at the University of Missouri[1]
- Northeast – based at the University of Medicine and Dentistry of New Jersey
- Southeastern – based at Meharry Medical College
- Western – based at the University of California, Los Angeles

The Curriculum Development Guide: An Overview

The RTCs, in collaboration with CDC and the National Organization on Fetal Alcohol Syndrome (NOFAS), developed the original *FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice*, released in 2009 (FASD Regional Training Centers Curriculum Development Team, 2009). The guide's competencies and accompanying content has been updated in this edition to reflect new knowledge and advances in the field. Like the first edition, it is a tool for developing a range of educational materials and training programs tailored to the needs of students and practitioners in the medical and allied health professions to prevent and treat FASDs.

The guide discusses seven competencies—the sets of knowledge, skills, and attitudes that enable a person to perform specific work. The updated competencies and a summary of each are as follows:

I. **Foundation:** *Demonstrate knowledge of the historical background of disorders related to prenatal exposure to alcohol, known collectively as fetal alcohol spectrum disorders (FASDs).*

The effects of prenatal alcohol exposure were first described in the medical literature in 1968 by Paul Lemoine of France (Lemoine, Harousseau, Borteyru, & Menuet, 2003). Subsequent human and animal studies have clearly demonstrated that prenatal exposure to alcohol is harmful to the fetus, resulting in physical malformations, growth problems, or abnormal functioning of the central nervous system. These negative effects, grouped under the umbrella term fetal alcohol spectrum disorders (FASDs), are lifelong and serious, and children born with prenatal alcohol exposure might have a range of

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[1] The Midwestern FASD RTC was formerly based at Saint Louis University until 2013 when the Principal Investigator relocated to University of Missouri.

problems, from subclinical effects to full fetal alcohol syndrome (FAS) (National Institute on Alcohol Abuse and Alcoholism, 2000). The significant morbidity and mortality issues potentially associated with these conditions warrant the training of medical and allied health professionals to advance the delivery of prevention and intervention services. Competency I serves as the foundation for the curriculum by summarizing the historical background related to identifying the effects of prenatal alcohol exposure; defining the spectrum of disorders; and examining the epidemiological, psychosocial, and cultural aspects of FASDs.

II.   **Alcohol Use Disorders:** *Apply concepts associated with alcohol use disorders (AUDs) to women of childbearing age, including those who are pregnant, and understand the appropriate level of intervention for those who have or are at risk of developing an AUD.*

Alcohol consumption is a public health issue–not only due to concerns for general health and safety but also as it relates to the numbers of women who report drinking alcohol while pregnant. Genetic and brain imaging research conducted over the past two decades has revealed that alcohol use can produce significant and prolonged changes in the brain's reward, cognition, inhibition, and motivation pathways, which can lead to an inability to control urges or cravings. These findings, along with evidence showing the efficacy of long-term treatment in managing addictions, suggest that alcohol use disorders should be considered chronic illnesses much like other conditions (e.g., diabetes) (Crome & McLellan, 2014). Recent research also shows that because women metabolize alcohol differently from men, they experience alcohol-related health consequences sooner and are more vulnerable to the telescoping effects from first use to alcohol-related medical problems and addiction (Johnson, Richter, Kleber, McLellan & Carise, 2005; Kay, Taylor, Barthwell, Wichelecki, & Leopold, 2010; Wilsnack, Wilsnack, & Kantor, 2014). Competency II provides an overview of AUDs, including the definition of a standard drink; consumption patterns and basic alcohol use epidemiology; research on the science of addiction; gender differences in alcohol-related health problems; and stigma associated with AUDs.

III.   **Alcohol Screening and Brief Intervention:** *Discuss the health problems addressed by alcohol screening and brief intervention (SBI), as well as the basic elements of alcohol SBI and how best to serve women at risk.*

Prevention needs to be viewed as a shared responsibility among all medical and allied health professionals and research suggests that routine, formal screening for alcohol use should be conducted with all adults. There are many readily-available research-based screening tools and physicians and other primary health care providers must receive information, training, and support to become comfortable and proficient in their administration. Following the alcohol screening, brief intervention has been shown to be an effective, low cost option to address risky drinking and alcohol-related harms, including preventing alcohol exposed pregnancies (Bien, Miller, & Tonigan, 1993; Fleming et al., 2010; Wilton et al., 2013). Competency III focuses on the elements of alcohol SBI implementation, overview of the evidence base and the components of brief intervention, and special factors to consider relating to alcohol use among women.

IV. Biological Effects of Alcohol on the Fetus: *Describe the effects of alcohol on the developing embryo and fetus.*

As a pregnant woman consumes alcohol and her blood alcohol level rises, the alcohol freely crosses the placenta and the embryo or fetus is exposed to the same blood alcohol levels as the mother. However, the fetus' liver and other organs are not yet fully developed or functioning during gestation. Thus, the fetus is unable to detoxify any of the alcohol before it reaches and acts upon emerging cells and organs. No single mechanism can explain all the harmful effects of alcohol on the developing fetus. However, a fetus prenatally exposed to alcohol is affected by a three-way interaction between amount (dose), timing, and subsequent postnatal environment (e.g., quality of home environment, exposure to violence, and eligibility for services). Competency IV provides an in-depth description of alcohol metabolism and pharmacology; biological effects of alcohol on the developing fetus; critical periods of fetal development and effects of alcohol on the nervous system; and genetic and other possible mechanisms of alcohol teratogenesis.

V. Screening, Diagnosis, and Assessment for Treatment Planning: *Screen, diagnose, and assess individuals for FASDs, including infants, children, adolescents, and adults.*

The screening of children and persons with possible effects from prenatal alcohol exposure is an important step in identifying FASDs. As prenatal alcohol exposure can affect the functioning of an individual across several domains, diagnosis is best made within the context of a multidisciplinary assessment of the individual (Manning & Hoyme, 2007). In the DSM-5, neurobehavioral disorders have qualifiers such as onset age and/or severity scales, as well as other qualifiers that can be "associated with a known medical or genetic condition or environmental factor." Health care professionals are able to document factors that may have contributed to the disorder's etiology and also how those factors affect a child on a clinical basis (American Psychiatric Association, 2013). Competency V provides a comprehensive discussion on the continuum of FASD; approaches to recognizing and diagnosing FASD and comorbidities, and referring individuals for in-depth evaluation.

VI. Treatment Across the Life Span for Persons with Fetal Alcohol Spectrum Disorders: *Provide long-term case management for persons with FASDs.*

Early intervention is critical in the treatment of individuals with an FASD. Across the life span, several protective factors have been associated with improved functioning for individuals with FASDs: stable nurturing care giving, early diagnosis, absence of violence, stable home placements, and eligibility for social and educational services (Streissguth et al., 2004). Connecting individuals and their family members/caregivers affected by FASD with resources and services helps support positive short- and long-term outcomes. Competency VI includes a discussion of the various age-specific developmental concerns related to FASDs; approaches to treatment; and support services and resources available to individuals and families impacted by these disorders.

VII. Ethical, Legal, and Policy Issues: *Recognize ethical, legal, and policy issues related to FASDs and alcohol use during pregnancy.*

FASD-related health care is laden with ethical issues, such as weighing the rights of a pregnant woman; protecting the health of the fetus; and providing optimal care for individuals with FASD. Health care practitioners who thoughtfully consider the ethical aspects of delivering such care are better able to meet the needs of individuals living with FASDs, thereby capitalizing on the opportunities for intervention that often requires a coordinated interplay among systems of care. Staying informed about the laws and policies related to alcohol use in pregnancy is important to understanding the expected parameters for acting within the law and providing ethical care for the women, fetuses, and children they serve. Competency VII provides a comprehensive discussion of ethical principles of healthcare and legal and policy issues for individuals and families living with FASDs, including the maternal-fetal relationship. Case examples are used throughout to increase understanding of the issues.

Persons who teach or organize courses, workshops, and other educational programs using this guide will determine specific learning objectives for each competency based on the participants' learning needs. Learner needs may include knowledge only or the ability to practice or teach.

The seven competencies in this guide address three key focus areas: prevention of alcohol-exposed pregnancies/FASDs, identification and care of individuals with FASDs, and ethics. Figure i.1 depicts these three key focus areas the competencies associated with each, and the medical or health care specialties most likely to benefit from learning about each of these.

Figure i.1. Matrix of Key Focus Areas and Related Competencies

Key Focus Area/Related Competencies	Medical/Health Care Specialty
Prevention of Alcohol-Exposed Pregnancies / FASDs **Related competencies:** **I, II, III, IV**	Nurses/Nurse Practitioners Obstetricians/Gynecologists Social Workers Family Physicians/Internists Medical Assistants
Identification and Care of Individuals with FASDs **Related competencies:** **I, IV, V, VI**	Pediatricians Social Workers Family Physicians/Internists Medical Assistants
Ethics **Related competencies:** **VII**	Nurses/Nurse Practitioners Pediatricians Obstetrician-Gynecologists Family Physicians/Internists Social Workers Medical Assistants

Educational experiences can be designed in a variety of formats (either classroom-based or distance learning-based) and tailored for the specific needs of an audience. Examples of educational formats include:

- Courses
- Workshops
- Seminars
- Grand rounds
- Video conferences
- Independent study opportunities

Each section of this guide contains detailed information on one of the seven competencies related to FASDs. For each competency, the following is given:

- Learning goals
- Content outline for the competency
- Suggested learning activities
- References and, in some cases, additional resources

An appendix provides a glossary of terms used in this guide, informational resources, and a listing of members of the curriculum development team.

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Competency I: Foundation

Joyce Hartje, PhD; Alexandra Edwards, MA; and Carolyn Edney, MSW

Competency I serves as the foundation for the entire curriculum and can be used as an introduction to trainings based on this Curriculum Development Guide. Upon completion of Competency I, the health care student or provider will be able to demonstrate knowledge of the historical background of disorders related to prenatal exposure to alcohol, known collectively as fetal alcohol spectrum disorders (FASDs).

Learning Goals

I-A   Summarize the background of the historical recognition of FASDs.

I-B   Describe the types of FASDs and effects of prenatal alcohol exposure.

I-C   Understand prevalence rates and societal costs related to FASDs.

Content Outline for Competency I

  I.   **Background and purpose of guide**

 II.   **Early recognition of the effects of prenatal alcohol exposure**

III.   **Fetal alcohol spectrum disorders (FASDs)**

IV.   **Epidemiological, psychosocial, and cultural aspects of FASDs**

Also included in this section are:

- Suggested learning activities
- Other resources
- References

I. Background and purpose of guide

Alcohol use is a global problem that compromises both individual and social development (World Health Organization, n.d.). The Centers for Disease Control and Prevention (CDC, 2014) reports that although at least 38 million adults drink too much (defined as binge drinking, high weekly use, and any alcohol use by pregnant women or those under age 21), most individuals who drink do not have an alcohol use disorder. Similar to the alcohol prevalence rates found in the 2006-2010 Behavioral Risk Factor Surveillance System (BRFSS) (CDC, 2012), the Substance Abuse and Mental Health Services Administration (SAMHSA, 2013) reports that slightly more than half (52.1%) or approximately 135.5 million Americans aged 12 or older reported being current drinkers. Nearly one-fourth (23.0%) of individuals in that age group reported binge drinking and 6.5% said they were heavy drinkers. Among non-pregnant women of childbearing age (15 to 44 years of age), 55.5% reported some alcohol use, 24.7% reported binge drinking, and 5.2% said they were heavy drinkers. In comparison, 8.5% of pregnant women (aged 15 to 44 years) responding to the same survey reported current alcohol use, 2.7% reported binge drinking, and 0.3% reported drinking heavily.

Despite the pervasiveness of alcohol consumption in the United States, only one in six adults report ever talking with their health care professional about their drinking (CDC, 2014). Unfortunately, this represents countless missed opportunities to help individuals who drink too much to drink less. Studies have shown that when health care professionals talk with patients about their alcohol use (i.e., alcohol screening and brief counseling/intervention), the amount of alcohol consumed on an occasion among those who drink too much can be reduced by 25%. Therefore, a key step to reducing the health and social costs associated with risky drinking patterns is to educate physicians, nurses, and other health care professionals on:

- Using a set of questions to screen all patients for the amount and frequency of their drinking;
- Counseling patients about the health consequences resulting from drinking too much; and
- Referring those few patients who need specialized alcohol use disorder treatment.

In addition to the health benefits that talking with patients holds for the general population, counseling women who are pregnant or who may be pregnant is crucial to reducing and preventing the number of alcohol-exposed pregnancies (AEPs). Human and animal studies have clearly demonstrated that prenatal exposure to alcohol is harmful to the fetus, resulting in physical malformations, growth problems, or abnormal functioning of the central nervous system (CNS). These negative effects are lifelong and serious, ranging from subclinical effects to full fetal alcohol syndrome (National Institute on Alcohol Abuse and Alcoholism [NIAAA], 2000). The significant morbidity and mortality issues potentially associated with these conditions warrant the training of medical and allied health professionals to advance the delivery of prevention and intervention services.

This Curriculum Development Guide provides a foundation for advancing understanding of the impact that prenatal alcohol exposure has on an affected individual across the lifespan. The information included in this Guide is designed to be used as a resource to inform development of

academic and professional training curricula for health care providers and can be tailored to meet the needs of various audiences.

II. Early recognition of the effects of prenatal alcohol exposure

Paul Lemoine of France first described the effects of prenatal alcohol exposure in the medical literature in 1968 (Lemoine, Harousseau, Borteyru, & Menuet, 2003). The most important breakthrough in understanding and documenting FAS in the U.S. came through the work of Jones, Smith, and colleagues (Jones & Smith, 1973; Jones, Smith, Ulleland, & Streissguth, 1973). They recognized and described a cohort of children who had similar facial dysmorphology and who had all been exposed to excessive amounts of alcohol in utero. Common to all of these children was a distinctive constellation of physical abnormalities, growth retardation, CNS damage, and prenatal alcohol exposure. Researchers determined that all the children in the study had suffered teratogenic damage due to maternal alcohol consumption during the gestational period. The term fetal alcohol syndrome (FAS) was introduced to describe the resulting condition.

Beyond the medical and research literature, FAS and the dangers of prenatal alcohol exposure were brought to public awareness by the book *The Broken Cord* (Dorris, 1989). In this book, Dorris described experiences with his adopted son, Adam, who had FAS, and explained the negative consequences of prenatal alcohol exposure in a way that could be understood by the general public.

As researchers looked at cases historically diagnosed as mental retardation and related conditions, they found that many might have actually been cases of FAS and other alcohol-related effects. A striking example of this was presented by Karp and colleagues who, in 1995, looked at work done by Henry Goddard, an American psychologist and eugenicist. In 1912, Goddard had published a book regarding the inheritance of "feeble-mindedness," a general early-20th century term referring to a variety of mental disabilities, including mental retardation and learning disabilities. Goddard's book followed the genealogy of the Kallikak family and compared two sides of the family tree: the "normal" side and the "feeble-minded" side. A re-analysis of family history, medical records, and photographs suggested that FAS and prenatal alcohol exposure offered a more valid explanation for the Kallikak family history of disabilities than genetics (Goddard, 1912; Karp, Quazi, Moller, Angelo, & Davis, 1995).

The U.S. Surgeon General issued the first public health advisory in 1981, warning that alcohol use during pregnancy could cause birth defects (Food and Drug Administration, 1981). That warning, which was reissued in 2005, is shown below in Figure 1.1.

Figure 1.1.   2005 U.S. Surgeon General Advisory on Alcohol Use in Pregnancy

Surgeon General's Advisory on Alcohol Use in Pregnancy

The discovery of FAS led to considerable public education and awareness initiatives informing women to limit the amount of alcohol they consume while pregnant. But 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 life-long. 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.

Source: US Department of Health and Human Services. (2005). *U. S. Surgeon General releases advisory on alcohol use in pregnancy*. Washington, DC: US Department of Health and Human Services.

III. Fetal alcohol spectrum disorders (FASDs)

Fetal alcohol spectrum disorders, or FASDs, is an umbrella term used to describe the range of effects attributed to prenatal alcohol exposure (Center for Disabilities, n.d.; Stratton, Howe, & Battaglia, 1996). The spectrum includes FAS, which is considered the most involved of the conditions along the continuum of FASDs and includes abnormal facial features, growth deficits, and CNS problems. Other conditions along the spectrum include alcohol-related birth defects (ARBD) that manifest with physical defects, and alcohol-related neurodevelopmental disorder (ARND) that exhibits by way of functional and/or cognitive impairments (Bertrand et al., 2004; Stratton et al., 1996). At present, consensus for diagnostic criteria only exists for FAS (Astley, 2006, 2011; Bertrand et al., 2004). The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), published by the American Psychiatric Association (APA) in 2013, lists criteria for assessing neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE) when evaluating a patient who has been exposed to alcohol in utero. Although ND-PAE is not an official diagnosis, APA suggests that it be further researched for formal inclusion in future DSM editions (APA, 2013).

Although fetal alcohol exposure affects all regions of the brain, some regions appear more vulnerable than others. Through technology such as magnetic resonance imaging, researchers have been able to document an overall reduction in brain size in children with FAS. Furthermore, several brain structures seem to be particularly susceptible to damage from prenatal alcohol exposure, including areas surrounding the interhemispheric fissure, the corpus callosum, the cerebellum, and the basal ganglia (NIAAA, 2000). Adverse effects on brain structures and development result in negative CNS effects and a wide variety of potential functional deficits. These can include: cognitive deficits (e.g., specific learning disabilities, poor academic achievement, discrepancy between verbal and nonverbal skills, slowed movements or reaction to people and stimuli); executive functioning deficits (e.g., poor organization and planning skills, concrete thinking, lack of inhibition, poor judgment); motor functioning delays or deficits (e.g., delayed motor milestones, clumsiness, balance problems, tremors, poor dexterity, difficulty with writing or drawing); attention and hyperactivity problems (e.g., distractability, overactivity, difficulty completing tasks, trouble with transitions); and social skills problems (e.g., lack of stranger fear, vulnerability to being exploited, immaturity, superficial interactions, inappropriate choice of friends, poor social cognition) (Bertrand et al., 2004).

Functional abilities vary greatly across individuals with FASDs due to differences in the dose and timing of exposure as well as postnatal environmental influence. However, functional deficits from prenatal alcohol exposure are lifelong disorders that children never outgrow. Some of the negative consequences of these deficits include disrupted school experiences, legal problems, incarceration, mental health problems, substance abuse, inappropriate sexual behavior, dependent living, and poor employment history. Often these types of problems are referred to as secondary conditions (Streissguth, Barr, Kogan, & Bookstein, 1996).

IV. Epidemiological, psychosocial, and cultural aspects of FASDs

As noted earlier, FAS is considered the most involved outcome from an AEP. Prevalence estimates for FAS have been difficult to determine for multiple reasons and, depending on

methods used, vary considerably. For example, using medical and other records, CDC reports FAS prevalence rates from 0.2 to 1.5 cases per 1,000 births across various populations in certain parts of the U.S. (CDC, 2002). CDC collected data from a multi-state study on the prevalence of FAS in children from 7 to 9 years of age in 2010 and found that 0.3 out of 1,000 children met the criteria for an FAS diagnosis (CDC, 2015). Few estimates for the full range of FASDs are available; however, analyzing community studies that used physical examinations conducted by experts, May and colleagues (2009; 2014) estimate that 2% to 5% of the U.S. population may be affected by the full range of FASDs. It is necessary to point out that FASDs may be underreported as the less severe cases may go undetected or be categorized as other behavioral conditions. This results in medical and other records that do not reflect the true prevalence of FASDs in society.

It has been documented that disadvantaged groups (e.g., American Indians/Alaska Natives and other minorities) have FAS prevalence rates as high as 3 to 5 cases per 1,000 children (Sampson et al., 1997). In a study among children in a foster care system, the prevalence rate for FAS was found to be 15 cases per 1,000 children (Astley, Stachowiak, Clarren, & Clausen, 2002). Finally, among individuals in one juvenile justice system, more than 200 per 1,000 (20%) were found to have FAS or a related disorder, supporting the idea that this population is disproportionately represented in the juvenile justice system (Fast, Conry, & Loock, 1999).

Annual costs associated with FASDs in the United States are estimated to be approximately $5 billion and the estimated lifetime cost for one individual with an FASD is $1.5 million (Thanh, Jonsson, Dennett, & Jacobs, 2011). Reported Medicaid costs incurred by children with FAS in 2011 were nine times higher than costs for children without FAS (Amendah, Grosse, & Bertrand, 2011). Costs associated with severe problems, such as profound mental retardation, are even higher (Lupton, Burd, & Harwood, 2004). It is important to note that cost estimates to date have only been available for FAS and that, as the awareness and understanding of the range of effects attributed to prenatal alcohol exposure increases, the reported costs associated with these disorders are expected to be much higher (Amendah et al., 2011; Lupton et al., 2004; Popova, Stade, Bekmuradov, Lange, & Rehm, 2011).

Finally, FASDs are considered as both birth defects and developmental disabilities, thereby increasing the burden on societal resources in a number of areas. For instance, individuals with FASDs have increased health care needs from birth through adulthood, as well as functional problems such as mental health difficulties, disrupted school and job experiences, trouble with the law, difficulties with independent living, and substance abuse (Bertrand et al., 2004; Streissguth et al., 1996). Furthermore, FASDs have serious and often devastating effects on the family (Streissguth, 1997). For example, parents of individuals with FASDs report clinically elevated levels of stress (Paley, O'Connor, Frankel, & Marquardt, 2006) and may need family support within many systems, including medical and health care, early intervention and education, juvenile justice and corrections, substance abuse treatment, mental health, and social services.

FASDs and the issues related to these disorders are an important public health priority, causing considerable unnecessary personal and societal burden. Health care practitioners are uniquely

positioned to help prevent AEPs and reduce this tremendous burden for women and their children and families.

Suggested Learning Activities

- Use descriptive case studies to discuss effects of FASDs.
- Use the "Critical Periods of Fetal Development" chart to illustrate fetal development and the effects of teratogens at different stages of development (see Competency IV, Figure 4.1).
- Lead a discussion of costs of FASDs to individuals and society.
- Have a small group develop a list of challenges in addressing FASDs, then list societal benefits in addressing alcohol use.
- Lead a discussion about perceptions of alcohol by first asking participants to name the first thing that comes to mind when they hear the word 'alcohol.' Write these down on a flip chart or whiteboard. Group the answers by those that are positive, negative, etc.

Other Resources

Federal Government Sites
- CDC's Fetal Alcohol Spectrum Disorders website: http://www.cdc.gov/fasd
- National Institute on Alcohol Abuse and Alcoholism: http://www.niaaa.nih.gov/
- National Institute on Drug Abuse: http://www.nida.nih.gov/
- SAMHSA's FASD Center for Excellence: http://www.fasdcenter.samhsa.gov/

Organizations
- March of Dimes: http://www.marchofdimes.com
- National Organization on Fetal Alcohol Syndrome (NOFAS): http://www.nofas.org
- The Arc of the United States: http://www.thearc.org

University Sites
- Fetal Alcohol and Drug Unit of the University of Washington: http://www.washington.edu/research/centers/184
- Fetal Alcohol Syndrome Diagnostic & Prevention Network, University of Washington: https://depts.washington.edu/fasdpn/

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Competency II: Alcohol Use Disorders

Joyce Hartje, PhD; Nancy Roget, MS; Carolyn Edney, MSW; and Emilie Cattrell, BA

The health care student or provider will be able to apply concepts associated with alcohol use disorders (AUDs) to women of childbearing age, including those who are pregnant, and understand the appropriate level of intervention for those who have or are at risk of developing an AUD.

Learning Goals

II-A Summarize the basic epidemiology of alcohol use.

II-B Identify health problems associated with risky and excessive alcohol use.

II-C Explain the ways in which alcohol impacts women differently from men.

II-D Discuss stigma associated with having an AUD.

Content Outline for Competency II

I. **Introduction**

II. **Alcohol use**
   A. Defining a standard drink
   B. Alcohol consumption patterns and basic epidemiology of alcohol use
   C. Diagnostic criteria
   D. Science of addiction research

III. **Alcohol risks for women**
   A. Gender differences in health problems associated with alcohol use
   B. Impact of alcohol on families

IV. **Stigma associated with alcohol use disorders**

Also included in this section are:

- Suggested learning activities
- Other resources
- References

I. Introduction

Alcohol consumption has been a widely accepted practice in many cultures for centuries (World Health Organization [WHO], 2014) and most people drink responsibly. For some, however, alcohol consumption progresses towards excessive use. It is important that health care providers and educators have a basic knowledge of alcohol use disorders (AUDs) to help their patients avoid the consequences associated with consuming amounts of alcohol that exceed weekly, daily, or per occasion limits, including the devastating effects of alcohol-exposed pregnancies. This competency provides an overview of what has been learned about AUDs and addiction in recent years, including recognizing AUDs as a chronic disease process, examining how the effects of alcohol differ in women compared to men, and addressing the stigma associated with AUDs.

II. Alcohol use

Risky and/or excessive alcohol consumption can be linked to a number of health, social, and economic issues. Globally in 2012, about 3.3 million deaths (5.9% of all deaths) and more than 200 disease and injury conditions (e.g., alcohol dependence, liver cirrhosis, cancers, HIV/AIDS, and injuries) were attributable to alcohol consumption (WHO, 2014). In the United States, excessive alcohol use accounts for approximately $224 billion per year in health care costs, as well as costs associated with lost productivity, crime, and incarceration (Bouchery, Harwood, Sacks, Simon, & Brewer, 2011; Crome & McLellan, 2014). Despite these consequences, the practice of screening, intervening, and treating AUDs has not been fully embraced by mainstream health care systems and remains a relatively low health policy priority.

Contributing to this seeming lack of awareness and attention to issues related to AUDs has been an ongoing public misperception that alcohol misuse and addiction is sinful, hedonistic, a moral failing, a sign of weak character, or a bad habit that will go away if the person's will is strong enough. However, genetic and brain imaging research conducted over the past two decades has revealed that alcohol use can produce significant and prolonged changes in the brain's reward, cognition, inhibition, and motivation pathways, which can lead to an inability to control urges or cravings. These findings, along with evidence showing the efficacy of long-term treatment in managing addictions, suggest that AUDs should be considered chronic illnesses much like other long-term conditions (e.g., diabetes).

Based on these and other research findings, there has been an increased demand for new political, organizational, and clinical efforts aimed at changing public awareness, opinion, and approach to dealing with the high cost and devastating effects associated with AUDs. This includes recognizing that social sanctions and punishments are not effective in reducing addiction; being aware of new medications and treatment interventions tested and found to be effective in clinical trials research; and expanding access to quality physical and behavioral health treatment services that are affordable (Crome & McLellan, 2014).

A. Defining a standard drink

To accurately assess whether or not a person is drinking too much, there must be a shared understanding of what constitutes a standard drink. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) (2005) defined a standard drink as "any drink that contains approximately 14 grams (about 0.6 fluid ounces) of pure alcohol," which is the amount contained in one 12-ounce beer or wine cooler, one 5-ounce glass of wine, or 1.5 ounces of 80-proof distilled spirits. It is important to note that these figures are estimates since the actual amount of alcohol varies based on the brand and type of beverage, as well as the size of the beverage container (see Figure 2.1). For example, eight to nine ounces of malt liquor is considered to be one standard drink based on the alcohol content of that beverage. However, many malt liquors are sold in 40-ounce containers, which is the equivalent of 4.5 standard drinks. Likewise, a typical 25-ounce (750 ml.) bottle of table wine holds five standard drinks. Thus, it is essential that patients be asked about the number of drinks they consume *and* the size of the container they used.

Figure 2.1.   Standard Drink of Alcohol

| STANDARD DRINK EQUIVALENTS	APPROXIMATE NUMBER OF STANDARD DRINKS IN:
BEER or WINE COOLER	
12 oz. **~5% ALCOHOL**	• 12 oz. = 1 • 16 oz. = 1.3 • 22 oz. = 2 • 40 oz. = 3.3
MALT LIQUOR	
8 – 9 oz. **~7% ALCOHOL**	• 12 oz. = 1.5 • 16 oz. = 2 • 22 oz. = 2.5 • 40 oz. = 4.5
TABLE WINE	
5 oz. **~12% ALCOHOL**	• 750-ml. (25 oz.) bottle = 5
80-PROOF SPIRITS (hard liquor)	
1.5 oz. **~40% ALCOHOL**	• 1 mixed drink = 1 or more* • 1 pint (16 oz.) = 11 • 1 fifth (25 oz.) = 17 • 1.75 L (59 oz.) = 39 *****Note**. Depending on the type of spirits and recipe, one mixed drink can contain multiple standard drinks

Source: NIAAA. (2005). *Helping Patients Who Drink Too Much: A Clinician's Guide*. Bethesda, MD: U.S. Department of Health and Human Services. NIH Pub. No. 07-3769.

B. Alcohol consumption patterns and basic epidemiology of alcohol use

Although many individuals drink alcohol, only a small percentage meet the diagnostic criteria for an AUD, including most that binge drink on a regular basis (Centers for Disease Control and Prevention [CDC], 2014). Epidemiological research has examined the quantity, frequency, and type of alcohol consumed by the general U.S. population and the range of negative consequences that may be experienced as a result of excessive drinking. Figure 2.2 illustrates the findings from this research, which have been consistent since the 1960s when data were first collected. In looking at the entire U.S. adult population, only about 4% of those who drink can be diagnosed as being alcohol dependent, or having a severe AUD as described in the Fifth Edition of the American Psychological Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM) new criteria (discussed later in this competency). Individuals in this category can experience negative consequences associated with their alcohol consumption and can benefit from receiving treatment from a trained substance abuse treatment professional.

Figure 2.2.   Prevalence of Excessive Alcohol Use in the United States
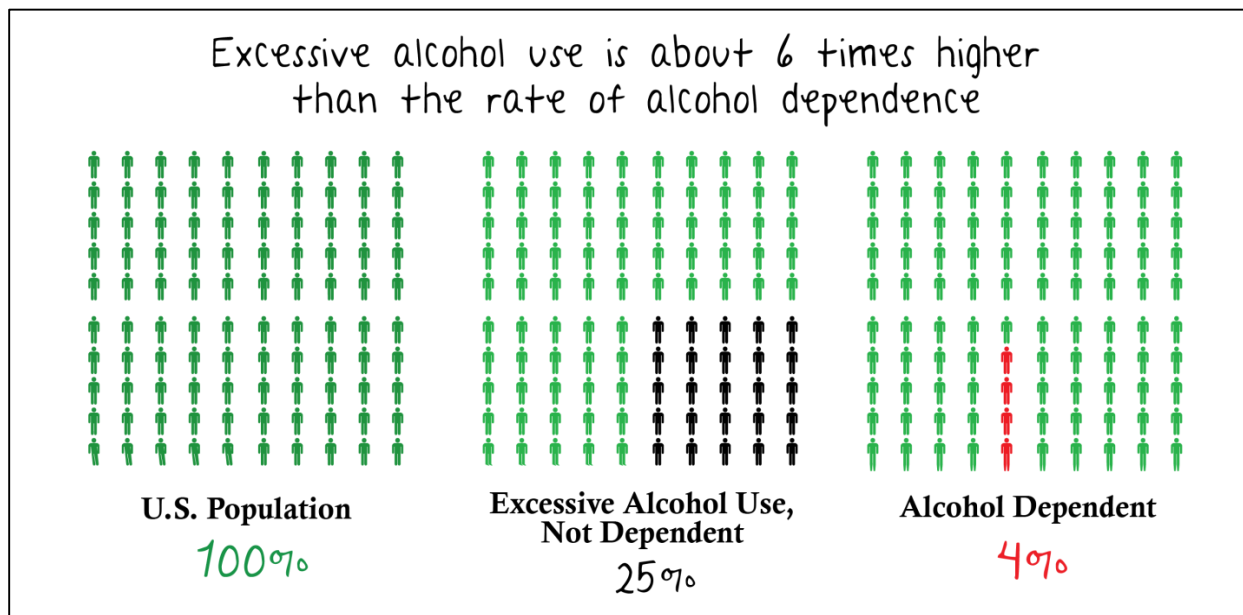
Source: Higgins-Biddle, J.C. (2012). Alcohol SBI: Implementation in primary care settings. Webinar: FASD Regional Training Centers-SBI Sub-committee. Centers for Disease Control and Prevention: Atlanta, GA.

The 25% of the population who drink excessively (i.e., consume alcohol in amounts that exceed established weekly, daily, or per occasion limits) but are not considered to be dependent can also experience negative consequences related to their drinking. This group can benefit from being identified through a validated screening process and receiving a brief intervention from their health care professional.

Conducting alcohol screening and brief intervention (SBI) is a way to help individuals recognize the possible risks associated with their alcohol consumption levels and patterns and provide excessive alcohol users the opportunity to reduce or eliminate their drinking patterns, thereby minimizing the negative consequences associated with the behavior. The strongest evidence and recommendation is for this intervention to be done with adults, including pregnant women, in

primary care settings. Those who need more specialized treatment, as revealed through screening, need to be referred for additional treatment services. See Competency III for a more detailed discussion of alcohol SBI.

In addition to the amount of alcohol consumed, it is important to assess a person's drinking pattern to determine the frequency of binge or heavy drinking. The Centers for Disease Control and Prevention (2013b) defines binge drinking as alcohol consumption that brings the blood alcohol concentration levels to 0.08g/dL, which usually occurs after consuming four drinks for women and five drinks for men within a 2-hour timeframe (see Figure 2.3).

Figure 2.3.   Defining Binge and Heavy Drinking

Binge Drinking	*Women*: 4 or more standard drinks during a single occasion (usually within a 2-3 hour time period)
	Men: 5 or more standard drinks during a single occasion (usually within a 2-3 hour time period)
Heavy Drinking	*Women*: more than 1 standard drink per day on average
	Men: more than 2 standard drinks per day on average

Source: CDC. (2013b). *Fact sheets – Alcohol use and your health*. Retrieved from http://www.cdc.gov/alcohol/fact-sheets/alcohol-use.htm

In 1984, CDC established the Behavioral Risk Factor Surveillance System (BRFSS; see: http://www.cdc.gov/brfss/), a nationwide surveillance system that annually conducts telephone surveys with more than 400,000 adults in all 50 states, the District of Columbia, and three U.S. territories. Data collected by the BRFSS focus specifically on the health-related risk behaviors, chronic health conditions, and use of preventive services of individuals aged 18 years and older. As part of that survey, four questions ask about the quantity and frequency of the individual's alcohol consumption. Based on responses to these items, an estimate of the percentage of the population who fall into the binge and heavy drinking categories can be calculated (see Figure 2.4). Results from the 2013 BRFSS showed that 55.4% of respondents consumed at least one drink of alcohol in the 30 days prior to the survey. Of this sub-sample, 16.8% were considered to be binge drinkers and 6.2% were considered to be heavy drinkers.

Figure 2.4.   Reported 30-Day Alcohol Use and Estimated Binge and Heavy Drinking Prevalence, 2013

BRFSS Item	2013
During the past 30 days, how many days per week or per month did you have at least one drink of any alcoholic beverage such as beer, wine, a malt beverage, or liquor?	Current drinkers 55.4%
• One drink is equivalent to a 12-ounce beer, a 5-ounce glass of wine, or a drink with one shot of liquor. During the past 30 days, on the days when you drank, about how many drinks did you drink on the average?	Binge drinking 16.8%
• Considering all types of alcoholic beverages, how many times during the past 30 days did you have [*5 for men; 4 for women*] or more drinks on an occasion?	Heavy drinking 6.2%
• During the past 30 days, what is the largest number of drinks you had on any occasion?	

Source: CDC. (2013a). *Behavioral Risk Factor Surveillance System (BRFSS)*. Retrieved from: http://www.cdc.gov/brfss/index.html

C. Diagnostic criteria

Diagnosis of an AUD is based on more than just a brief screening of an individual's alcohol use. In addition to assessing the amount and frequency of use, medical professionals use the World Health Organization's International Classification of Diseases (ICD) criteria and behavioral health professionals use the APA's DSM to diagnose AUDs. The DSM was originally developed to establish a "nationally acceptable psychiatric nomenclature" for diagnosing patients with severe psychiatric and neurological disorders. Since 1952, it has provided the diagnostic classification, diagnostic criteria sets, and descriptive text; served as the standard classification of mental disorders used by mental health practitioners; and become a valuable tool for researchers in the collection of consistent public health statistics in the United States.

In May 2013, the APA released the Fifth Edition of the DSM (DSM-5). Although some overlap exists between the DSM-5 and DSM-IV (see Figure 2.5 for a comparison), substantive changes were made in the chapter on *Substance-Related and Addictive Disorders* that are intended to more accurately represent the experiences of individuals who have an AUD and eliminate confusion regarding the terminology associated with the disorders (APA, 2013b; NIAAA, 2013a). These changes were also intended to bring the DSM-5 more in line with the ICD criteria for diagnosing AUDs. In making revisions for the DSM-5, the APA workgroup reviewed extensive research and analyzed data from numerous studies to identify clinically appropriate changes to the criteria (Hasin et al., 2013). Of particular note is the integration of two DSM-IV disorders (alcohol abuse and alcohol dependence) into a single disorder (AUD) that is measured on a continuum with mild, moderate, and severe sub-classifications (APA, 2013b; NIAAA, 2013a). The new criteria can be considered within four overall groups: impaired control (Criteria 1–4); social impairment (Criteria 5–7); risky use (Criteria 8–9); and pharmacological criteria (Criteria 10–11) (Lewniak, 2013). Although neither tolerance nor withdrawal is necessary for an AUD diagnosis, past history of withdrawal is often associated with a more severe clinical course (Lewniak, 2013).

Figure 2.5.   Comparison between the DSM-IV and DSM-5 Criteria

DSM IV		DSM 5	
Recurrent alcohol use resulting in a failure to fulfill major role obligations at work, school, or home (e.g., repeated absences, suspensions, or expulsions from school; neglect of children or household).	1	Alcohol is often taken in larger amounts or over a longer period than was intended. (See DSM-IV, criterion 7.)	The presence of at least 2 of these symptoms indicates an **Alcohol Use Disorder (AUD)**.
Recurrent alcohol use in situations in which it is physically hazardous (e.g., driving an automobile or operating a machine when impaired by alcohol abuse).	2	There is a persistent desire or unsuccessful efforts to cut down or control alcohol use. (See DSM-IV, criterion 8.)	
Recurrent alcohol-related legal problems (e.g., arrests for alcohol-related disorderly conduct). **– This is not included in DSM-5 –**	3	A great deal of time is spent in activities necessary to obtain alcohol, use alcohol, or recover from its effects. (See DSM-IV, criterion 9.)	The severity of the AUD is defined as:
Continued alcohol use despite having persistent or recurrent social or interpersonal problems caused or exacerbated by the effects of the	4	Craving, or a strong desire or urge to use alcohol. **– This is new to DSM-5 –**	**Mild**:

(Left margin label for DSM IV rows: **Any 1 = ALCOHOL ABUSE**)

	alcohol (e.g., arguments with spouse about the consequences of intoxications, physical fights).		The presence of 2 to 3 symptoms.
Any 3 = ALCOHOL DEPENDENCE	Tolerance, as defined by either of the following: a) A need for markedly increased amounts of alcohol to achieve intoxication or desired effect b) Markedly diminished effect with continued use of the same amount of alcohol	5	Recurrent alcohol use resulting in a failure to fulfill major role obligations at work, school, or home. (See DSM-IV, criterion 1.)	**Moderate**: The presence of 4 to 5 symptoms.
	Withdrawal, as manifested by either of the following: a) The characteristic withdrawal syndrome for alcohol b) Alcohol is taken to relieve or avoid withdrawal symptoms	6	Continued alcohol use despite having persistent or recurrent social or interpersonal problems caused or exacerbated by the effects of the alcohol (See DSM-IV, criterion 4.)	**Severe**: The presence of 6 or more symptoms.
	Alcohol is often taken in larger amounts or over a longer period than was intended.	7	Important social, occupational, or recreational activities are given up or reduced because of alcohol use. (See DSM-IV, criterion 10.)	
	There is a persistent desire or unsuccessful efforts to cut down or control alcohol use.	8	Recurrent alcohol use in situations in which it is physically hazardous. (See DSM-IV, criterion 2.)	
	A great deal of time is spent in activities necessary to obtain alcohol (e.g., driving long distances), use alcohol, or recover from its effects.	9	Alcohol use is continued despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to have been caused or exacerbated by the substance. (See DSM-IV, criterion 11.)	
	Important social, occupational, or recreational activities are given up or reduced because of alcohol use.	10	Tolerance, as defined by either of the following: a) A need for markedly increased amounts of alcohol to achieve intoxication or desired effect b) A markedly diminished effect with continued use of the same amount of alcohol (See DSM-IV, criterion 5.)	
	Alcohol use is continued despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to have been caused or exacerbated by the substance (e.g., continued drinking despite recognition that an ulcer was made worse by alcohol consumption).	11	Withdrawal, as manifested by either of the following: a) The characteristic withdrawal syndrome for alcohol (refer to criteria (a) & (b) of the criteria set for alcohol withdrawal) b) Alcohol (or a closely related substance, such as a benzodiazepine) is taken to relieve or avoid withdrawal symptoms. (See DSM-IV, criterion 6.)	

Source: NIAAA. (2013a). Alcohol use disorder: A comparison between DSM-IV and DSM-5 (NIAAA Publication no. 13-7999). Washington, DC: U.S. Government Printing Office. Retrieved from http://pubs.niaaa.nih.gov/publications/dsmfactsheet/dsmfact.htm

Using the DSM-IV diagnostic criteria, anyone meeting one or more of items 1 through 4 within a 12-month period would be diagnosed with "alcohol abuse"; meeting three or more of items 5 through 11 during a 12-month period would result in an "alcohol dependence" diagnosis. Under the DSM-5 criteria, meeting any two of the 11 criteria during the same 12-month period would warrant a diagnosis of AUD, with the severity of the disorder (mild, moderate, or severe) based

on the number of criteria met. The DSM-5 also eliminates legal problems as a criterion, adds craving as a criterion for an AUD diagnosis, and updates language in some of the descriptions.

Critics of the DSM-5 suggest that the more inclusive criteria may lead to a reported increase in prevalence rates (Edwards, Gillespie, Aggen, & Kendler, 2013). There also are concerns that combining abuse and dependence could result in a "mild alcohol use disorder" diagnosis for someone who occasionally binge drinks or has a one-time negative experience involving alcohol, which could potentially have long-lasting consequences (National Council on Alcoholism and Drug Dependence, Inc, 2012). Although proponents believe these concerns are unfounded and cite extensive research comparing DSM-IV and DSM-5 diagnostic criteria to support the changes, additional research is needed on the use of the new criteria to ascertain the extent of impact on research and practice (Hasin et al., 2013; Edwards et al., 2013).

D. Science of addiction research

Many individuals use alcohol and other drugs because of the immediate change in how they feel, often in terms of better mood, alertness, etc. (Nutt & McLellan, 2014). Studies have shown that 40-60% of a person's tendency toward addiction can be attributed to genetics and gene-environment interactions (i.e., added impact of the environment on how genes function or are expressed). For example, a person has certain risk factors for heart disease, such as a family history, smoking, and obesity. While people can't change their genetic predisposition to develop heart disease, they can reduce their risk by not smoking and losing weight. Likewise with alcohol, altering environmental (non-biological) risk factors can reduce the probability that a person will develop an AUD (Volkow, Fowler, & Wang, 2003).

Genetic, biological, and environmental risk factors can increase vulnerability to the reinforcing effects of alcohol. However, repeated use can cause changes in the brain that drive compulsive use, even for individuals without significant risk factors. To better understand why individuals continue to use alcohol despite negative consequences, current research has turned to neuroscience to examine the effects on the brain.

The structure and function of the human brain includes what is referred to as a 'brain reward pathway,' or circuit, that evolved to motivate behaviors that ensure survival of the species (Volkow, Chandler, & Fletcher, 2009). Dopamine is the main neurotransmitter, or chemical messenger, of the brain reward pathway. Many physiological activities (e.g., exercise, sex, and eating) cause the release of neurotransmitters, including dopamine, which produce pleasurable and rewarding experiences, and enhance motivation to continue the activity (Nutt & McLellan, 2014; Volkow et al., 2009). Alcohol and drugs of abuse also release neurotransmitters, often more rapidly and in higher levels than physiological activities. This rapid release of reward-inducing neurotransmitters is thought to be a significant part of an individual transitioning from exploratory to regular to compulsive use, despite negative consequences (i.e., addiction) (Nutt & McLellan, 2014; Volkow et al., 2009).

Individuals most likely begin using alcohol intentionally but interactions between alcohol use, genetic vulnerability, and particular environmental circumstances that appear to determine the eventual course of continued use remain a mystery. Researchers in the addictions field believe

that neuroscience will have a tremendous influence on creating drug policy and expanding clinical interventions for addictions. First, given what the research shows about the cascading effect of repeated alcohol use, prevention and early interventions need to be expanded to prevent the potential long-term neurological, genetic, emotional, and behavioral changes associated with addiction. Second, addiction treatment will likely need to be "chronic" (or ongoing) to offset the complex neurological factors associated with severe addiction, displacing "acute care-oriented" short-term therapies aimed at educating and motivating patients to stop drinking. Next, although it seems counterintuitive to use one drug to help control abuse of another, medications can be an appropriate option for treating addiction. Development of personal recovery and social supports is not always enough to prevent relapse. Finally, because of the changes in the individual's brain as a result of their drinking, the practice of punishments designed to "teach addicts a lesson" about alcohol abuse need to be curtailed since they have little or no impact on changing behavior (Nutt & McLellan, 2014).

Evidence-based practices. A number of evidence-based practices (EBPs) are currently being used to effectively identify and treat individuals who have or are at risk of developing an AUD. Although a full discussion of these modalities is beyond the scope of this competency, the following are a few of the more commonly known interventions:

- Cognitive Behavioral Therapy (CBT)
- Motivational Enhancement Therapy (MET)
- Motivational Interviewing (MI)
- Pharmacotherapy (e.g., Acamprosate, Naltrexone, Disulfiram)
- Screening and Brief Intervention (SBI)
- 12-Step Facilitation (Alcoholics Anonymous)

In addition to implementing EBPs in face-to-face treatment settings, many AUD treatment providers are starting to use telehealth technologies (e.g., video conferencing; telephone; mobile apps) to deliver services in an effort to expand access to treatment and recovery services to more individuals (e.g., those living in rural, remote, or frontier areas of the country). For more information on resources and training opportunities on EBPs, as well as new approaches to delivering treatment and recovery services, visit the following websites:

- Addiction Technology Transfer Centers (ATTC): http://www.attcnetwork.org/home/
- Centers for Disease Control and Prevention: http://www.cdc.gov/pwud/substance-treatment.html
- National Frontier and Rural Addiction Technology Transfer Center: http://nfar-attc.org
- National Institute on Alcohol Abuse and Alcoholism: http://www.niaaa.nih.gov/alcohol-health
- NIDA/SAMHSA-ATTC Blending Initiative: http://www.attcnetwork.org/projects/blendinginitiative.aspx

III. Alcohol risks for women

In 2011, one-third (33.3%) of the women admitted for substance abuse treatment reported alcohol as their primary substance of abuse (SAMHSA, 2014). Until recently, the majority of research on problems associated with alcohol use was based on studies of men and findings generalized to make assumptions about alcohol use among women (Mann et al., 2005). However, research now shows that the effects of alcohol consumption are much different for women than for men. The consequence of not understanding this difference is that problems reported by women can often be misunderstood, misdiagnosed, or simply ignored, when in fact they are serious alcohol-related issues (Vandermause & Wood, 2009).

A. Gender differences in health problems associated with alcohol use

Women typically have a lower body weight, smaller liver capacity to metabolize alcohol, and higher proportion of body fat. Likewise, medical studies indicate that women absorb and metabolize alcohol differently than men due to a lower level of the alcohol metabolizing enzyme alcohol dehydrogenase (ADH) in the stomach. All these factors together lead to a larger proportion of the ingested alcohol reaching the blood, resulting in higher blood alcohol levels (BAC) in women after consuming the same amount of alcohol as men (Kay, Taylor, Barthwell, Wichelecki, & Leopold, 2010; NIAAA, 2013b). Consequently, women are more vulnerable to the telescoping effects of alcohol use, meaning that women progress more quickly than men from first use to alcohol-related medical problems and addiction (Johnson, Richter, Kleber, McLellan, & Carise, 2005; Kay et al., 2010; Wilsnack, Wilsnack, & Kantor, 2014). For example, alcohol-dependent females compared to alcohol-dependent males are more likely to: die prematurely; experience serious cardiovascular disease; develop fatty liver, alcoholic hepatitis, and cirrhosis; have hypertension, impaired immune function, and metabolic disturbances; show brain abnormalities and psychiatric disorders; gain weight and have nutrition disturbances; be diagnosed with diabetes; be affected by osteoporosis; and develop certain types of cancer (e.g., breast, lung, upper and lower digestive, genital, and urinary) (Allen et al., 2009; Boyle & Boffetta, 2009; Kay et al., 2010; Mann, Batra, Günthner, & Schroth, 1992; Seitz, Pelucchi, Bagnardi, & LaVecchia, 2012). Furthermore, women who drink during pregnancy increase the risk of FASDs and other health problems in their newborns (Streissguth et al., 2004; Viljoen et al., 2005).

Many societies hold more negative attitudes towards women drinking alcohol than men drinking, especially when the women are engaging in heavy, harmful drinking. Depending on the culture, these attitudes may increase women's vulnerability to social harm. Similarly, women are affected by interpersonal violence and risky sexual behavior as a result of their own drinking problems and the drinking behavior of male partners (Morojele, Brook, & Kachieng'a, 2006; Kalichman, Simbayi, Kaufman, Cain, & Jooste, 2007).

B. Impact of alcohol on families

Alcohol use impacts not only the individual with the AUD, but also their families and particularly their children. According to a Substance Abuse and Mental Health Services Administration (SAMHSA, 2009) report, using combined data from 2002 to 2007, over 8.3

million children under 18 years of age (11.9%) lived with at least one parent who was dependent on or abused alcohol or an illicit drug during the year prior to the survey. Of these, almost 7.3 million (10.3%) lived with a parent who abused or was dependent on alcohol, compared to about 2.1 million (3.0%) who lived with a parent who abused or was dependent on an illicit drug. These data provide a basis for increased concerns about child abuse and neglect, injuries and deaths related to motor vehicle accidents, and likelihood that the children will themselves abuse or become dependent on alcohol or drugs. They highlight the need for substance abuse treatment for the affected adults, as well as prevention and supportive services for the children to strengthen personal and social attributes that help protect against developing an addiction. Although some of these attributes, like genetic predisposition, cannot be changed, others may be tapped to help people with strong genetic risk for alcohol abuse avoid developing addictions.

Family risk and protective factors. The primary domains of developmental risk and protective factors for abuse and dependence (addiction) are based on the Risk and Protective Factor theory developed by Hawkins, Catalano, and Miller (1992). This theory identifies "contextual factors" that increase or reduce the likelihood of alcohol, tobacco, and other substance use. Risk factors are those things that increase the probability of an individual engaging in behavior that likely has negative consequences, whereas protective factors decrease that probability and help individuals and families attain positive development goals. Figure 2.6 provides examples of risk and protective factors in each of the primary domains of development (Chandler, Fletcher, & Volkow, 2009).

Figure 2.6.   Risk and Protective Factors Associated with Substance Abuse and Addiction

Risk Factors	Protective Factors
Individual	
▪ Genetic predispositions ▪ Early and persistent antisocial behavior ▪ Mental health/psychiatric disorders ▪ Association with peers/friends who engage in problem behaviors ▪ Early initiation of the problem behavior	▪ Activities with non-using peers ▪ Parental monitoring of friends and activities ▪ Resilient temperament ▪ Positive social orientation
Community	
▪ Availability of alcohol/drugs ▪ High crimes/community norms favorable toward alcohol/drug use ▪ Low neighborhood attachment ▪ Extreme economic deprivation	▪ Health community substance use & behavior norms ▪ Positive community activities/role models ▪ Work ▪ Anti-drug use policies ▪ Policies limiting availability of alcohol
Family	
▪ Family history of problem behavior ▪ Family management problems ▪ Major or frequent family conflicts/disruptions ▪ Parental attitudes and substance use/abuse ▪ Crime, violence, abuse/neglect	▪ Bonding/attachment to positive family members ▪ Healthy family beliefs ▪ Favorable parental attitudes ▪ Clear standards regarding substance use & behavior ▪ Recognition for positive behaviors/successes
School	
▪ Learning problems/disability ▪ Poor grades/academic performance/failure beginning in elementary school ▪ Lack of commitment and behavior problems at school ▪ Expulsion/suspension	▪ Success in school ▪ Parental monitoring of academic performance/school behavior ▪ Involvement in group activities ▪ Positive recognition for good behaviors and successes

Source: Temple, J.R. & Stuart, G.L. (2009). Risk and protective factor theory. In G.L. Fisher and N.A. Roget (Eds.), Encyclopedia of substance abuse prevention, treatment, & recovery (pp. 795-797). Thousand Oaks, CA: Sage Publications.

Three additional points should be noted regarding risk and protective factors. First, the more risk factors present in an individual's life, the greater the probability that alcohol abuse problems will develop. Therefore, when multiple risk factors are present, it makes sense to reduce the ones that can be changed if possible. Second, the relationship between risk factors and problem behaviors is correlational, not cause and effect. Therefore, someone with numerous risk factors is not "doomed" to addiction. In other words, "*Risk does not equal destiny.*" Finally, absence of risk factors does not mean that individuals are protected from alcohol abuse problems. For example, someone with no risk factors who drinks alcohol every day will likely develop a dependence on alcohol. Thus, "*No risk does not equal total protection.*"

IV. Stigma associated with alcohol use disorders

AUDs are among the most stigmatized conditions (Glass, Mowbray, Link, Kristjansson, & Bucholz., 2013b), with some suggesting that individuals who abuse alcohol do so freely and voluntarily, and continue to use despite negative consequences because they have a weak will or character (Buchman & Reiner, 2009). Research conducted on stigma towards alcohol and other drug users compared to other groups (e.g., mental illness and physical disability) suggests that public stigma (i.e., attitudes among the general public) towards substance use is higher on dimensions of social distance (a willingness to interact with an individual) and negative emotions (feelings about interacting with an individual) (Brown, 2011). Attitudes, which can be "learned cognitive, affective, and behavioral predispositions to respond positively or negatively to certain objects, situations, institutions, concepts, or persons" (Aiken, 2002, p. 3), can motivate individuals' behavior and affect perception of various subgroups in society (Eagly & Chaiken, 1993). The basis of stigmatizing attitudes has been described as "elements of labeling, stereotyping, separation, status loss, and discrimination occurring together in a power situation that allows them" (Link & Phelen, 2001, p. 363).

From the individual's perspective, stigma can be grouped into three categories: perceived stigma (awareness of public stigma); experienced stigma (actual occurrences of discrimination attributed to a condition); and self-stigma (negative evaluations associated with public stigma incorporated into one's sense of self) (Brohan, Slade, Clement, & Thornicroft, 2010). For individuals with AUDs, the perception of being devalued or discriminated against by others (e.g., family, friends, colleagues, health care professionals) can serve as a barrier to accessing treatment and be detrimental to achieving and sustaining recovery (Glass et al., 2013b; Laudet, 2008; White, 2007; White, 2009). This perceived stigma can also be associated with poorer mental health, higher rates of depression, lower quality of life, and poorer physical health (Glass, Kristjansson, & Bucholz 2013a). In addition, individuals or their family members may experience a high degree of embarrassment about their AUD (i.e., self-stigma), resulting in low expectations for treatment success, which in turn discourages them from seeking services (Brown, 2011). Finally, in an attempt to avoid further stigmatization, individuals labeled as "alcoholics" or "addicts" may become secretive about their use to avoid uncomfortable social interactions, which then leads to additional negative outcomes (e.g., damaged relationships, smaller social network, lack of social support, and increased alcohol consumption and depressive symptoms) (Glass et al., 2013a).

Similarly, the attitudes of health care professionals can influence the ways in which those professionals approach, communicate, and interact with their alcohol-using patients (i.e., experienced stigma). For example, most individuals with AUDs initially see their health professional for other physical ailments, which provides an opportunity for the professional to screen for and talk with their patients about risky or problem alcohol use. However, studies show that many health care professionals express negative attitudes towards patients with AUDs, potentially having a negative influence or delaying the diagnosis, treatment, and recovery of AUDs (van Boekel, Brouwers, van Weeghel, & Garretsen, 2013). Identifying and eliminating stigma associated with AUDs and addiction will require an increased emphasis on developing and implementing trainings for medical and allied health professionals. Providing education focused on the underlying causes and chronic nature of addiction is the best hope for reducing

negative attitudes and improving treatment access, recovery success, and overall health for individuals suffering from these diseases.

Suggested Learning Activities

- Lead a discussion about alcohol use disorders, including the science of addiction research.
- Lead a discussion on alcohol consumption patterns and basic epidemiology of alcohol use and how changes in the DSM-5 might impact the diagnostic criteria for alcohol use disorders.
- Discuss case studies related to gender differences in health problems associated with alcohol use and the impact of alcohol use on families.
- Use case studies or scenarios to guide discussions about stigma associated with alcohol use disorders and drinking alcohol while pregnant.

Other Resources

- Beyond Hangovers: Understanding Alcohol's Impact on Your Health http://pubs.niaaa.nih.gov/publications/Hangovers/beyondHangovers.pdf
- Rethinking Drinking http://rethinkingdrinking.niaaa.nih.gov/
- The Anonymous People – a feature documentary film about the over 23 million Americans living in long-term recovery from alcohol and drug addiction http://manyfaces1voice.org/

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Competency III: Alcohol Screening and Brief Intervention

Georgiana Wilton, PhD; Leigh Tenkku Lepper, PhD, MPH; and Sandra Gonzalez, MSSW, LCSW

The health care student or provider will be able to discuss the health problems addressed by alcohol screening and brief intervention (SBI), as well as the basic elements of alcohol SBI and how best to serve women at risk.

Learning Goals

III-A   Explain the basic elements of alcohol SBI implementation based on CDC's *Planning and Implementing Screening and Brief Intervention for Risky Alcohol Use: A Step-by-Step Guide for Primary Care Practice.*

III-B   Describe the basic elements of brief intervention and the range of options to administer alcohol SBI.

III-C   Discuss special factors relating to alcohol use among women.

Content Outline for Competency III

I.   The elements of alcohol SBI implementation
- A.   Use of validated screens to identify risky drinking
- B.   Administration of brief screens
- C.   Considerations and adaptations when screening

II.   The basic elements of brief intervention
- A.   Overview of evidence base
- B.   Components of brief intervention
- C.   Characteristics of interviewer
- D.   Alternative delivery of brief intervention
- E.   Brief intervention examples

III.   Special factors relating to alcohol use among women
- A.   Factors influencing alcohol use

IV.   Summary

Also included in this section are:

- Suggested learning activities
- References

Alcohol screening and brief intervention (SBI) is an effective, cost-efficient clinical preventive service that helps persons who drink too much to drink less. Alcohol SBI also helps identify individuals who indicate potential dependence on alcohol facilitating referral to treatment services. Risky or excessive alcohol use is a significant problem resulting in 88,000 deaths annually in the United States (Centers for Disease Control and Prevention [CDC], 2004).

I. The elements of alcohol SBI implementation

A. Use of validated screens to identify risky drinking

There are many reliable and readily available methods appropriate for screening women of childbearing age for risky drinking behaviors (Midanik, Zahnd, & Klein, 1998). The primary care setting is ideal for screening, and primary care providers are in a unique position to ask their patients about alcohol use. Unfortunately, this setting is not used as widely as it might be. To do so, physicians and other primary health care providers must receive information, training, and support to become comfortable and proficient in their administration.

Absolute confidentiality cannot be maintained in all circumstances, and this must be conveyed to the patient. Further, if there is a suspicion of inaccurate reporting of alcohol use, primary care providers must work to increase comfort and trust of the patient over time so that eventually an environment of increased safety and trust will facilitate more accurate reporting. In a system where alcohol screening is conducted as a routine part of primary care, there is time to build this relationship.

When screening for risky drinking, it is important to consider levels of consumption as well as drinking patterns (Dawson, Smith, Pickering & Grant, 2012; Kerr & Stockwell, 2012; Livingston, 2013). Despite substantial literature on the validity and reliability of self-report of alcohol use and abuse (reviewed in Babor, Brown, & del Boca, 1990; Sobell & Sobell, 1990), the issue of underreporting of drinking levels may need to be taken into account. When asking heavier drinkers and those consuming high-alcohol-content beverages about their consumption, reliance on standard drink charts may result in considerable underestimation. Despite the popularity and increased availability of high-alcohol-content beverages, studies have shown that individuals do not change their pattern of drinking based on alcohol concentration by volume (Kerr & Stockwell, 2012). That is, they continue to drink as many high-alcohol-content beverages as lower-alcohol-content beverages. For these reasons, the first step in any screening protocol should be to define a standard drink (see Competency II).

Quantity/frequency. Quantity-frequency (QF) measures inquire about average or typical consumption patterns (Sobell & Sobell, 1995). The simplest measures assess amount of drinking on average drinking days (Q), and the average number of days on which alcohol is consumed (F). To assess for binge drinking, some researchers recommend that screening questions include measures of maximum quantity consumption and frequency of maximum quantity (QVM) (Day & Robles, 1989).

Using QF measures, non-pregnant women who consume more than seven drinks per week or who have drinking episodes of more than three drinks are considered high risk (National Institute on Alcohol Abuse and Alcoholism [NIAAA], 2005). For pregnant women, there is no known safe amount of alcohol during pregnancy.

B. Administration of brief screens

While many evidence-based screening tools exist, most do not provide the necessary information on how much a patient is drinking or their pattern of consumption, and are more appropriate when screening for alcohol use disorders than risky drinking. (CDC, 2014, p. 36) This section presents the basic tools that are available to assess information to determine 'risky drinking.'

Figure 3.1.   Recommended Initial Screening Options

Single Question Alcohol Screen:
> How many times in the past year have you had X drinks in a day?
> ➢ X represents 4 for women and 5 for men
> ➢ A response of 1 or more is considered a positive screen

AUDIT 1-3 (US):

QUESTIONS	0	1	2	3	4	5	6	Score
1. How often do you have a drink containing alcohol?	Never	Less than Monthly	Monthly	Weekly	2–3 times a week	4–6 times a week	Daily	
2. How many drinks containing alcohol do you have on a typical day you are drinking?	1 drink	2 drinks	3 drinks	4 drinks	5–6 drinks	7–9 drinks	10 or more drinks	
3. How often do you have X (5 for men; 4 for women & men over age 65) or more drinks on one occasion?	Never	Less than monthly	Monthly	Weekly	2–3 times a week	4–6 times a week	Daily	
							Total	

Source: Adapted from CDC. (2014). *Planning and Implementing Screening and Brief Intervention for Risky Alcohol Use: A Step-by-Step Guide for Primary Care Practices.* Atlanta, Georgia: Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities.

To provide an appropriate intervention, more information can be captured through additional assessment (i.e., AUDIT) if time allows (CDC, 2014). See Competency II for additional information.

The use of screening tools developed for adults is not recommended for screening adolescents and college-age youth. In fact, the U. S. Preventive Services Task Force Recommendation Statement (Moyer, 2013) concludes "the current evidence is insufficient to assess the balance of benefits and harms of screening and behavioral counseling interventions in primary care settings to reduce alcohol misuse in adolescents." (p.1)

For more information on assessing alcohol use and brief screening tools, see:
http://pubs.niaaa.nih.gov/publications/AssessingAlcohol/index.htm

C. Considerations and adaptations when screening

Little has been published on the effectiveness of brief alcohol screening on adolescents and adults with intellectual disabilities. Assessing individuals with intellectual disabilities will vary based on level of disability and the underlying cause of the disability (Powers, 2005). In general, issues to consider include an individual's level of understanding, specificity in terminology (concrete vs. abstract), educational background, and other issues that may interfere with understanding (Substance Abuse and Mental Health Services Administration [SAMHSA], 2005). The abstract nature of brief screens may be confusing and lead to inaccuracy in reporting. Below are just a few examples of possible misinterpretations of screening questions:

1. How many times in the past year have you had X drinks in a day?
    Possible misinterpretation: Individual may not consider 'drinks' to include 'alcoholic' drinks. It must be specified that the question refers to 'drinks containing alcohol' with specific examples given.
2. How often do you have X or more drinks on one occasion?
    Possible misinterpretation: Individual may not understand what 'occasion' means. The specific timeframe must be defined using concrete definitions rather than loose guidelines (e.g., How often do you have 4 or more drinks in any one day?).

When working with individuals with intellectual disabilities, it may be necessary to gather additional data when assessing for risky drinking. Options to consider include: a biochemical marker, behavioral changes, the onset of psychiatric problems or unexplained health problems, or decline in function (Powers, 2005).

For additional information, see *SAMHSA TIP 29: Substance Use Disorder Treatment for People with Physical and Cognitive Disabilities*: http://store.samhsa.gov/product/TIP-29-Substance-Use-Disorder-Treatment-for-People-With-Physical-and-Cognitive-Disabilities/SMA12-4078

II. The basic elements of brief intervention

A. Overview of evidence base

Brief intervention has been shown to be an effective, low-cost option to address risky drinking and alcohol-related harms. It incorporates time-limited self-help and prevention strategies to promote reductions in alcohol use in non-dependent individuals and, in the case of alcohol-dependent persons, to facilitate referral to specialized treatment programs (Bien, Miller, & Tonigan, 1993; Fleming et al., 2010; Wilton et al., 2013). Typically performed in a clinical setting that is not specific for alcohol use disorders, brief intervention has been shown to be more effective than no intervention and often as effective as more extensive intervention. As noted by Jones, Bailey, and Sokol (2013), brief interventions delivered to pregnant women who have reported alcohol consumption have resulted in better outcomes at delivery, including maternal abstinence and decreased mortality rates. In 2013, the U.S. Preventive Services Task Force reviewed the evidence and recommended alcohol SBI (for those who screen positive) for all adults in primary care, including pregnant women.

B. Components of brief intervention

Six elements characterize key ingredients of brief intervention, summarized by the mnemonic FRAMES (Miller & Sanchez, 1993). These include:
- **F**eedback of personal risk
- **R**esponsibility for personal control
- **A**dvice to change
- **M**enu of ways to reduce or stop drinking
- **E**mpathetic counseling style
- **S**elf-efficacy or optimism about cutting down or stopping drinking

A key distinction of brief intervention is motivational enhancement. Motivational interventions are strategies designed to increase a patient's motivation to change and rely heavily on motivational interviewing techniques (MI). MI is a therapeutic style intended to reduce ambivalence and increase readiness to change (SAMHSA, 2002). The goal is to enhance discrepancy between the reasons for changing and the reasons for staying the same (Miller & Rolnick, 2012). Most brief interventions rely on MI or MI techniques (readiness ruler) and cognitive behavior therapy techniques. While MI involves specialized training and practice, even short-term training can improve clinical skills by teaching simple MI techniques to use with patients. For a review of MI and training resources, see:
http://www.motivationalinterviewing.org/

Brief intervention may also involve establishing a drinking goal in the form of a signed contract and follow-up of progress with ongoing support.

Figure 3.2.   Example of Brief Intervention for a Pregnant Woman

FEEDBACK AND RESPONSIBILITY
"You have already done many good things to help your baby be healthy. You mentioned that you are having _____ drinks on occasion. I'd like to talk with you about that if that's ok. You can reduce risks to your baby if you reduce your alcohol use. Babies exposed to alcohol during pregnancy might have some developmental and behavioral problems. It's up to you to decide if you want to change your drinking. "

ADVICE TO CHANGE
"The best advice for a pregnant woman is not to drink any alcohol."

 "What do you think about what I have just said? Would you like to work with me to quit or reduce your drinking?"

MENU OF WAYS TO REDUCE RISKY SITUATIONS FOR DRINKING
"People drink for different reasons. Here are examples of risky situations for some people: at a party, on weekends, after arguments, when feeling uptight or stressed, when feeling angry, when smoking, when friends are drinking, when feeling sad, when wanting to fit in. Are there situations in which you feel like you want to drink?"

"It is important to figure out how you can resist drinking in risky situations. Here are some examples of ways in which people cope with a desire to drink: go for a walk, call a friend, grab a snack, listen to music. Can you tell me some ways you think you can avoid drinking in these risky situations?"

ESTABLISHING A DRINKING GOAL
"Now, thinking about how much alcohol you have told me that you drink, would you like to set a drinking goal? Would you like to stop or lower your alcohol use? A reasonable goal for someone who is pregnant is abstinence—not drinking any alcohol. I know some people find that total abstinence is difficult. What would you like to do? What goal would you like to set for yourself? Stop drinking altogether or cut down?"

SET A GOAL
Encourage abstinence. Agree on number of drinks per week.

SELF-EFFICACY
"On a scale of 1 to 10, how sure are you that you can stop (lower) your drinking? 1 means you think you CANNOT stop (cut down) your drinking and 10 means you are sure you CAN stop (cut down) your drinking."

"If you feel that you cannot stop drinking right now, we can talk about some ways to reduce your risk.
- Add water to hard liquor (whiskey, rum, gin).
- Drink no more than one drink per hour.
- Eat food when you drink.

> - Sip your drinks.
> - Do not drink from the bottle.
> - Drink water or juice instead of alcohol.
> - Drink no more than three per drinking occasion."
>
> ENCOURAGEMENT AND FOLLOW-UP
> "Changing your behavior can be hard.
> - Remember your drinking goal.
> - Some people have days when they drink too much. If this happens to you, DO NOT GIVE UP.
> - At the end of each week, think about how many days you did not drink and congratulate yourself.
> - Your follow-up visit is important. Please remember to come see me."

Source: Adapted from O'Connor, M. J., & Whaley, S. E. (2007). Brief intervention for alcohol use by pregnant women. American Journal of Public Health, 97(2), 252-258.

C. Characteristics of interviewer

Supportive, nonjudgmental techniques that involve acceptance and compassion in a spirit of partnership should be the foundation of the intervention relationship (Miller & Rollnick, 2012). The most effective intervention approaches focus on reduction of alcohol use without criticism or provocation of guilt (NIAAA, 1997). Effective interventionists have been found to have a thorough knowledge of the intervention technique, an optimistic attitude about change, a compassionate style, sincerity and respect for clients, an ability to avoid arguments that evoke patient defensiveness, and comfort discussing alcohol problems (Miller & Rollnick, 1991; Najavits & Weiss, 1994).

D. Alternate delivery of brief intervention

The efficacy of alcohol brief intervention has been documented for decades in medical, educational, and community settings (Doumas & Hannah, 2008; Schulte et al., 2014; Wilton et al., 2013). In addition, a variety of administration modes have been tested and have been shown to be efficacious. As the use of technology increases, brief interventions have been expanded beyond the original in-person administration.

In-person brief intervention. In-person brief interventions have shown success in reducing alcohol use and alcohol-related harms (Fleming, Lund, Wilton, Landry, & Scheets, 2008). This traditional method involves a one-on-one patient/client meeting with an interventionist who provides personalized feedback and facilitates positive change. These can range from very brief interventions (under 10 minutes) conducted by clinicians in primary care settings (Selway, 2006) to 4-session manualized interventions to reduce the risk of an alcohol-exposed pregnancy (Floyd et al., 2007).

Telephone brief intervention. Telephone intervention has been used to effectively reduce risky drinking (Lin et al., 2010; Mello et al., 2013) and the risk of an alcohol-exposed pregnancy

(Wilton et al., 2013). Scripted interventions or motivational interviewing-based counseling can be effectively conducted via telephone. Telephone-based interventions can be cost-effective, minimize no-shows, reduce travel costs, and avoid time lost from work (Wilton et al., 2013).

Computerized brief intervention. A recent review of computer-based interventions focused on alcohol use revealed that within a six month period, nearly 60,000 people had visited an internet-based drinking assessment site, giving clear indication that the general public will use internet-based sites for achieving health promotion goals (Vernon, 2010). For a review of electronic alcohol SBI, see: http://www.thecommunityguide.org/alcohol/eSBI.html.

A potential tool for administering the brief intervention is "video doctor technology" in which health questions are asked using an interactive computer program. In one study, Gerbert and colleagues (2003) developed a patient-centered, supportive, nonjudgmental intervention based on motivational interviewing. A laptop computer program presented an actor-portrayed doctor asking health questions and delivering advice about drinking. The program employed branching logic that allowed users to customize the content of the presentation according to their gender, level of drinking, readiness to change, and desire for information. To foster a sense of self-efficacy among users, the messages provided personal feedback, allowed users to make their own choices about changing, gave recommendations, and offered suggestions for making changes. Pilot results of this approach indicate that individuals respond positively to a computerized presentation. Most recently, Lotfipour and colleagues (2013) utilized a computerized mechanism (CASI) that is based upon methods used in alcohol SBI through an interactive questionnaire on a touch screen tablet. The system is able to quickly identify and separate non-drinkers and those below the NIAAA threshold and, if necessary, provide a brief intervention at the end. User friendly systems such as CASI produce results consistent with other computerized brief interventions for alcohol use, allowing for better compliance for both the health care providers and the patients.

While avatar or "video doctor technology" and tablet interfaces become more prevalent for administering interventions, it is important to note that as technology continues to flourish the possibilities of computerized brief interventions can continue to expand.

Texting. The World Health Organization (WHO) identified mobile technology as a medium that has the potential to transform health care delivery (2011), and text messaging has been identified by health care patients as potentially beneficial in reducing risky drinking (Thornley, Kool, Marshall, & Ameratunga, 2014).

Suffoletto and colleagues (2012) examined the potential and efficacy for text messaging based alcohol screening and implementation for brief interventions. They found they were better able to follow up with patients (93% of participants responded to the weekly text messages) and offer a convenient outlet to provide constant screening and intervention for each individual's level of alcohol consumption. Further, weekly text messaging and subsequent responses were found to reduce the number of heavy drinking days in young adults.

In addition, a meta-analysis that examined the efficacy of text messaging alcohol and tobacco interventions showed that text interventions resulted in the reduction of substance abuse in adolescents and young adults (Mason, Ola, Zaharakis, & Zhang, 2014).

E. Brief intervention examples

There are many no-cost brief intervention print manuals and web-based options available. A few samples are listed below.

> Adolescents:
> Alcohol Screening and Brief Intervention for Youth: A Practitioner's Guide:
> http://niaaa.nih.gov/publications/clinical-guides-and-manuals/alcohol-screening-and-brief-intervention-youth/resources
>
> Adults:
> Helping Patients Who Drink Too Much: A Clinician's Guide:
> http://www.niaaa.nih.gov/guide
>
> Rethinking Drinking: http://rethinkingdrinking.niaaa.nih.gov/
>
> Alcoholscreening.org: www.alcoholscreening.org

There are fewer evidence-based interventions targeted toward women at risk of an alcohol-exposed pregnancy. One such model is CHOICES[1]. This intervention is dual focused, targeting both alcohol use and contraception behavior. Aimed at non-pregnant women who are sexually active, drinking above recommended levels, and not using effective contraception, this 4-session intervention provides education, explores ambivalence, and provides tools to help women make healthy choices (Floyd et al., 2007).

CHOICES is available at no cost, and successful adaptations of CHOICES from 2-4 sessions have shown efficacy (Balachova et al., 2013; Wilton et al, 2013). See:
http://www.cdc.gov/ncbddd/fasd/documents/choices_onepager_-april2013.pdf

III. Special factors relating to alcohol use among women

There is variation in both drinking patterns among women and risk of developmental outcome following intrauterine alcohol exposure. The mechanisms for this variation relate, in part, to the magnitude and timing of alcohol exposure in addition to a number of demographic and other risk factors.

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[1] The CHOICES name was initially an acronym that stood for *Changing **H**igh-Risk Alc**O**hol Use and **I**ncreasing Contraception Effectiveness Study*. It is now simply referred to as CHOICES.

A. Factors influencing alcohol use

Age.
Teens and college-age women.
Alcohol use among adolescents is a serious problem. According to the Substance Abuse and Mental Health Services Administration (SAMHSA), 24% of girls aged 12-20 report drinking alcohol (2013) and 20% report binge drinking (described as four or more drinks) (CDC, 2013).

Rates of alcohol use and early sexual intercourse are higher in early-maturing girls, placing them at a higher risk for adolescent pregnancy (Deardorff, Gonzales, Christopher, Roosa, & Millsap, 2005). Based on the growing rates of girls entering puberty at younger ages and the associated social implications, the risk of an alcohol-exposed pregnancy in this group is significant.

Many teens bring established drinking habits with them to college. Over 60% of college students ages 18-22 report drinking alcohol in the previous month and 40.1% engage in binge drinking (SAMHSA, 2013). Furthermore, high-risk drinking among female college students is increasing. The Harvard School of Public Health College Alcohol Study examined nationwide college alcohol use trends in four separate surveys between 1993 and 2001 (Wechsler, Lee, Kuo, & Lee, 2000; Wechsler & Nelson, 2008). In these surveys, researchers observed that, in contrast to recent trends, there was a sharp rise in frequent binge drinking among females. These trends exist in disquieting contrast to the increased college and community prevention efforts conducted during the same period.

Those drinking before age 14 are at greater risk of developing alcohol dependence (Hingson, Heeren, & Winter, 2006). Additionally, women who start drinking earlier in life are least likely to stop drinking during pregnancy and more resistant to intervention (Hingson, Heeren, Winter, & Wechsler, 2003).

Women of childbearing age.
Alcohol use among women of childbearing age (18 to 44 years) has remained high. Government surveys indicate that approximately 51.5% of non-pregnant women reported some alcohol use in the past 30 days. Further, 1.4% of pregnant women reported binge drinking in the past 30 days (defined as four or more drinks in any one occasion) (CDC, 2012; NIAAA, 2005). Despite lower rates of binge drinking among pregnant women, levels of consumption and patterns of drinking were similar among the two groups.

These high levels of general consumption and risky drinking among non-pregnant women of childbearing age are of concern because pre-pregnancy drinking status is predictive of alcohol use during pregnancy (SAMSHA, 2004). Therefore, identifying women who are at high risk for pregnancy and intervening with them before conception is an essential strategy for preventing alcohol-exposed pregnancies.

Pregnancy/breastfeeding status.

Pregnancy intention
A woman's intention to become pregnant may play an important role in her alcohol use prior to and upon becoming pregnant. Xaverius and colleagues (2009) found that among women intending a pregnancy, those at low, moderate, and high risk for having an alcohol-exposed pregnancy were all more likely than pregnant women to drink any alcohol and to drink at heavy and binge levels of alcohol use. Women with higher education who intend to get pregnant were 29% less likely to binge drink compared to those not intending a pregnancy (Tenkku Lepper, Dickhut, Swatch, & Cassady, 2015).

Pregnant women
Risky drinking has not decreased in women despite robust findings that prenatal drinking is associated with significantly increased negative consequences on fetal growth and child development, and despite significant universal prevention efforts in the form of public service announcements and warning labels on alcohol (SAMHSA, 2013). Given the increased risk of infant morbidity and mortality associated with prenatal alcohol exposure, it is vital to obtain the most accurate information regarding alcohol use during the preconception period.

Nursing mothers
Studies have shown that infants consume less milk when their mothers have an alcoholic beverage before nursing than when their mothers consume a nonalcoholic beverage (Mennella, 2001). Acute exposure to alcohol in mothers' milk has been shown to alter infants' sleep-wake patterns, resulting in a reduction in active sleep. In addition to effects of maternal alcohol consumption on infant nutrition and development, an infant's sensory experience with alcohol in mother's milk might affect future responses to alcohol (Mennella, 2001). For these reasons, it is important for health professionals to discuss alcohol consumption with nursing mothers.

Race, ethnicity, and acculturation. Drinking patterns appear to differ among women from different ethnic backgrounds and are influenced by genetic, environmental, historical, and cultural factors. White women drink more on average when compared to other population groups (CDC, 2012). However, upon pregnancy discovery, it appears that white women are more likely to report quitting or reducing their drinking compared to black, Hispanic, and American Indian/Alaskan Native women (Morris, Tenkku, Salas, Xaverius, & Mengel 2008; Tenkku, Morris, Salas, & Xaverius, 2009; Tenkku, Salas, & Xaverius, 2010). The three primary predictors for quitting either heavy or binge drinking include: being of younger age; not being a smoker; and having received prenatal care. Beyond these predictors, only having had no physical abuse was a predictor for quitting binge drinking among Black, non-Hispanic, Hispanic, and Asian/Pacific Islander women (Tenkku, Salas & Xaverius, 2010).

Historically, Hispanic women have shown increased alcohol consumption with each successive generation following immigration to the United States (Gilbert, 1991). More recently, Hispanic women have similar binge rates compared to non-Hispanic white and black women (CDC, 2013).

Asian-American women are much more likely than their male counterparts to abstain or consume less alcohol, although this is assumed to be due to perceived embarrassment from experiencing facial flushing while drinking (Collins & McNair, 2002). Stress and social adjustment have been considered factors contributing to drinking behavior among Asian immigrants (D'Avanzo, Frye, & Fromen, 1994). Acculturation has been found to explain, at least partially, the observed differences in drinking levels among young Asian Americans. Among college students, more highly acculturated students have reported higher levels of alcohol consumption than less acculturated students (Hahm, Lahiff, & Guterman, 2004; Wong, Klingle, & Price, 2004).

National rates of alcohol use among American Indians are difficult to estimate, as significant variance exists between tribes and between gender and age groups (Young & Joe, 2009). While some researchers have reported higher rates for alcohol abuse among American Indian populations compared to other racial/ethnic groups in the U.S. (Dickerson et al., 2011; Spillane, Cyders, & Maurelli, 2012), others have reported similar or lower rates than other racial/ethnic groups (Quintero, 2000; Watt, 2012). In fact, when other factors are controlled (e.g., socioeconomic status and regional location), rates may not differ significantly (Quintero, 2000; Watt, 2012). Regardless of specific use comparisons, what is consistently reported in the literature is that alcohol use and misuse is a large contributor to high rates of mortality and morbidity in the Native American population and represents a major public health concern.

Socio-economic status (SES). The correlation between SES and long term health is well understood: individuals with less education and lower income have an increased risk for disease and premature death (Matthews, Gallo, & Taylor, 2010). However, similar correlations for alcohol consumption are mixed. In a study examining the association of socioeconomic status with health behaviors and mortality over a span of 24 years, both male and female participants who were in lower socioeconomic positions were more likely to abstain from alcohol consumption and were less likely to consume heavy amounts of alcohol. Furthermore, among participants in the lowest socioeconomic position, alcohol abstention increased. Heavy consumption of alcohol was more prevalent among participants in the highest socioeconomic position for both men and women (Stringhini et al., 2010).

On the other hand, Matthews et al. (2010) found a lack of health care, poor nutrition, and excessive alcohol intake to be more likely among individuals with low SES. Therefore, the astute clinician will assess alcohol use for all patients regardless of SES.

Genetic influences. Both animal and human studies have shown support for pharmacogenetic differences dictated by genetic variations in ethanol metabolism as determinants of susceptibility to alcohol-related effects (Goodlett, Marcussen, & West., 1990; McCarver, 2001). The mechanism underlying this varying susceptibility might involve genetic differences in ethanol metabolism catalyzed by alcohol dehydrogenase (ADH). ADH isozymes arising from functional variants in the ADH2 gene catalyze the oxidation of ethanol at different rates (Dick & Foroud, 2003). Several studies have shown that individuals who carry the ADH2*2 or the ADH2*3 alleles are less likely to become alcohol dependent than those who do not (Chen et al., 1999; Dick & Foroud, 2003; Wall, Carr, & Ehlers, 2003). The mechanism of protection might be

related to the fact that women with the ADH2*2 and ADH2*3 alleles metabolize alcohol more quickly and efficiently, thereby exposing the fetus to lower blood alcohol concentrations. Although the observation of the protective effect of certain genotypes has been found to be statistically significant, and the direction of the effect is consistent for maternal and offspring genotypes and for offspring growth and development, the magnitude of effects on infant outcome has been found to be relatively small. Thus, the interaction of other environmental and/or genetic factors must be considered as contributors to the varying susceptibility of offspring exposed to ethanol prenatally.

Depression. A wide range of studies have highlighted the link between alcohol use disorders and major depression (Foulds et al., 2015). The presence of either condition doubles the risk of the other, and symptoms are not entirely accounted for by common factors influencing both (Boden & Fergusson, 2011). Further, in postpartum mothers determined to be drinking at risky levels, brief alcohol intervention not only reduced alcohol consumption but also symptoms of postpartum depression (Wilton, Moberg, & Fleming, 2009). Therefore, a consideration of both risks is important when treating a patient for either individual risk.

IV. Summary

Research to date suggests routine, formal screening for alcohol use should be conducted with all women of childbearing age, including pregnant women, and brief interventions conducted for those who screen positive. Screening can be done in both physicians' offices and in community health settings. The simple screening tools shown in this manual have been found to be beneficial for both non-pregnant and pregnant women. Further, brief interventions conducted by clinicians have a strong evidence base of success in reducing alcohol use and potentially alcohol related harms—including alcohol-exposed pregnancies.

Suggested Learning Activities

- Assign topics using section headers (women of childbearing age, etc.) for small groups to research and present to the group.
- Lead a group discussion of barriers and opportunities for screening.
- Role play screening techniques from diverse clinical fields (physician, nurse, medical assistant, etc.)
- Explore intervention examples from YouTube and discuss strengths and weaknesses of each example.
- Explore the brief intervention examples listed in this chapter. Role play sections or engage in discussion of usage with diverse women.

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Competency IV: Biological Effects of Alcohol on the Fetus

P. Kevin Rudeen, PhD and G. Bradley Schaefer, MD, FAAP, FACMG

The health care student or provider will be able to describe the effects of alcohol on the developing embryo and fetus.

Learning Goals

IV-A Explain alcohol metabolism and pharmacology (absorption, distribution, metabolism, and elimination).

IV-B Describe birth defects associated with alcohol use.

IV-C Describe alcohol-induced injuries on developing organ systems.

IV-D Describe cellular responses to alcohol exposure.

IV-E Explain putative biomedical mechanisms.

IV-F Describe genetic variants and markers for susceptibility for FASDs.

Content Outline for Competency IV

I. Alcohol metabolism and pharmacology

   A. Absorption
   B. Distribution
   C. Metabolism and elimination

II. Neuromorphological birth defects associated with alcohol use

   A. FAS
   B. FASDs

III. Alcohol-induced injuries on developing organ systems

   A. Sensitivity throughout gestation
   B. Postnatal effects of alcohol abuse

VI. Cellular response to alcohol exposure

   A. Neurogenesis

   B. Growth and differentiation of neurons
   C. Migration
   D. Synaptogenesis
   E. Apoptosis
   F. Plasticity

V. Putative biomedical mechanisms

   A. Neuromorphological and neurotrophic effects
   B. Effects on neurotransmitter receptors

VI. Genetic variants and markers

   A. Traditional features of teratogenic agents and their effects
   B. Emerging concepts in the pathogenesis of alcohol-medicate teratogenesis

Also included in this section are:

- Suggested learning activities
- References

I. Alcohol metabolism and pharmacology

To appreciate the effects of alcohol on the fetus, it is important to understand basic principles of alcohol pharmacokinetics and metabolism (National Institute on Alcohol Abuse and Alcoholism [NIAAA], 1997). Consider what happens when a pregnant woman takes a drink.

A. Absorption

When ethanol in a drink is introduced into the stomach, absorption (and metabolism) of the molecule (C_2H_5OH) occurs rapidly. The absorption rate might be influenced by other contents in the stomach; ethanol is most rapidly absorbed from an empty stomach. Peak blood ethanol concentrations are attained approximately one hour after consumption of the beverage, but this might vary depending on a number of factors, including the rate at which the alcoholic beverage was consumed; whether or not it was consumed with other substances, such as food; and the individual's rate of gastric emptying and body habitus (body mass, etc.).

Given the same amount of alcohol under standardized conditions, women attain consistently greater blood ethanol concentrations than men (NIAAA, 1999). This is largely the result of two factors. First, women's body water (the compartment in which the ethanol distributes) is significantly smaller than that of men. Second, women have a higher rate of alcohol absorption from the stomach than men. These factors are important given their significance to the embryo or fetus if the woman were pregnant.

B. Distribution

Compartmentalization. Body mass might be thought of as either water or non-water compartments. The content of the cell is nearly 98% water. Because of alcohol's rapid solubility in water, it can easily cross cell membranes into the cell. Alcohol is less soluble into lipids and compartments with substantial lipids; these non-water compartments are affected less readily by alcohol.

Absorption of alcohol from the stomach and gastrointestinal system into the blood vascular system occurs rapidly. Alcohol then moves readily through the water compartments, such as the blood plasma, extracellular fluids, and intracellular fluids. It is distributed throughout most organs of the body, including the musculoskeletal system, liver, kidney, heart, breasts, and nervous system (brain, spinal cord, and peripheral nerves).

Placental effects and fetal distribution. Normally there is no mixing of maternal and fetal blood. However, the capillaries containing the maternal blood and those containing the fetal blood are separated only by a minute barrier in the placenta so as to facilitate exchange of oxygen and nutrients from the mother to the fetus and carbon dioxide and wastes from the fetus to the mother. The placenta acts as a selective barrier but, unfortunately, does not discriminate among some substances, such as some drugs and viruses. Because of its

physical properties, alcohol is easily passed by diffusion from the maternal blood into the fetal blood (Little & Vanbeveren, 1996).

Once the alcohol is absorbed into the fetal circulation, it is distributed by the fetal blood vascular system throughout the fetal tissues in much the same manner as it is distributed in the mother. The alcohol partitions among the fetal compartments much as it does in the mother, with alcohol reaching concentrations in nearly all tissues similar to that of the mother (Akesson, 1974).

The embryo has limited ability to metabolize alcohol, mostly because of the status of the development of the liver and enzymes responsible for metabolism of ethanol (Pikkarainen & Räihä, 1967). Much of the ethanol that is passed from the mother into the embryo is eliminated from the embryo by diffusion back into the mother for metabolism and elimination.

C. Metabolism and elimination

Ethanol metabolism follows a principle known as "zero-order kinetics," meaning the rate is not limited by enzyme availability, but rather alcohol is metabolized dependent on its concentration. In zero-order kinetics, the disappearance of alcohol from the blood (or tissue) can be mathematically estimated and has a predictable disappearance; when plotted on a graph over time, it occurs in a straight line (Salaspuro & Lieber, 1978).

Most of the ethanol is metabolized in the liver; less than 10% is eliminated in the urine or by the lungs (via the breath). All metabolism pathways lead to the same product, acetaldehyde, which is then metabolized by an enzyme called acetaldehyde dehydrogenase (ALDH). ALDH metabolizes acetaldehyde to acetate, which is then metabolized into carbon dioxide and water.

Acetaldehyde and ALDH are significant to alcohol consumption since acetaldehyde has been shown to have systemic effects, such as general vasodilation (flushing), and a feeling of general malaise. Genetic or polymorphic variants of the ALDH gene might influence ethanol consumption in some populations (Chambers & Jones, 2002; Stoler, Ryan, & Holmes, 2002). Individuals carrying the variant form of the gene (allele) have a markedly reduced capacity to metabolize acetaldehyde resulting in some individuals having a reduced propensity to consume alcohol.

Fetal metabolism. Numerous scientific studies have been conducted in animals and humans to determine the amount of alcohol metabolized by either the placenta or the fetus. Best estimates indicate the placenta does not metabolize ethanol well (Akesson, 1974). The compilation of the studies also suggests that the capacity for ethanol metabolism by the embryo or fetus increases with gestational age.

Because the liver hepatocyte performs most of the alcohol metabolism through the alcohol dehydrogenase (ADH) pathway, these enzymes must be present and active for the fetus to be able to effectively metabolize alcohol. An embryo or early fetus lacks the enzymes for

metabolism, so the mother must metabolize most of the alcohol. The alcohol in the embryo or early fetus must diffuse back into the mother for oxidation and elimination. Because removal of the alcohol in the embryo largely occurs by simple diffusion back into the mother, embryonic alcohol levels might be higher than those in the mother and be present for a more prolonged but variable time (Burd, Blair, & Dropps, 2012). The prolongation of the alcohol concentration and the time that exposure might occur could be significant to the developing embryo or fetus.

II. Neuromorphological birth defects associated with alcohol use

A. FAS

To describe the neuromorphological birth defects associated with fetal alcohol syndrome (FAS), one must consider the effects of alcohol on neural and cognitive development and understand how molecular and cellular effects result in morphological and functional changes (Ladue, Streissguth, & Randels, 1992; Stratton, Howe, & Battaglia, 1996; Streissguth, Barr, Kogan, & Bookstein, 1996).

Early studies were descriptive in nature, attempting to determine which part or parts of the nervous system affected by fetal alcohol exposure contributed to the constellation of features associated with FAS. Multiple studies found that gross morphological changes were present in the brains of individuals who had FAS. These included significant developmental abnormalities in the cerebral cortex, such as microcephaly, hypoplastic or atrophic gyri and sulci, malformed or displaced gyri, porencephaly, and other malformations. Similar malformations have been described in the cerebellum, cerebellar cortex, and hippocampus. Indeed, it seems no area of the brain is resistant to the effects of fetal alcohol exposure (Mattson, Jernigan, & Riley, 1994; Mattson, Riley, Delis, Stern, & Jones, 1996). Similar malformations were observed in animal models subjected to fetal alcohol exposure.

More recent investigations into the morphological changes that occur as a result of fetal alcohol exposure indicate the presence of significant changes in the corpus callosum, the major connecting pathway between the two halves of the cerebral cortex. Fetal alcohol exposure might cause predictable alterations in the corpus callosum structure that are detectable by magnetic resonance imaging (MRI) or sonography (Bookstein, Sampson, Connor, & Streissguth, 2002). Because alterations in brain structure may influence facial features, facial image analysis has been utilized in an attempt to automate FAS diagnosis (Fang et al., 2008).

B. FASDs

Fetal alcohol spectrum disorders (FASDs) is an umbrella term that encompasses several diagnoses resulting from in utero exposure to alcohol. It is not intended as a clinical diagnosis, but rather a collective term for more specific diagnoses. Diagnoses included under this umbrella are: fetal alcohol syndrome, neurobehavioral disorder associated with prenatal alcohol exposure, partial FAS, and alcohol-related birth defects. Most clinicians are

aware of FAS, the most involved condition within the spectrum for surviving children with both physical and neurodevelopmental features. However, FAS does not encompass the full complement of diagnoses under the umbrella of FASDs. Specific criteria exist for diagnosis of FAS, and more recently for ND-PAE; however, research continues to provide more clinical clarity for all conditions within the spectrum.

It is important to note that many individuals with FASDs other than FAS might not have craniofacial effects of FAS, but have secondary behavioral and cognitive effects resulting from the alcohol exposure.

III. Alcohol-induced injuries on developing organ systems

Figure 4.1 depicts the critical periods of development and susceptibility to effects of alcohol and other teratogens. This discussion will be limited to the effects of ethanol on the nervous system.

Figure 4.1.   Critical Periods of Fetal Development
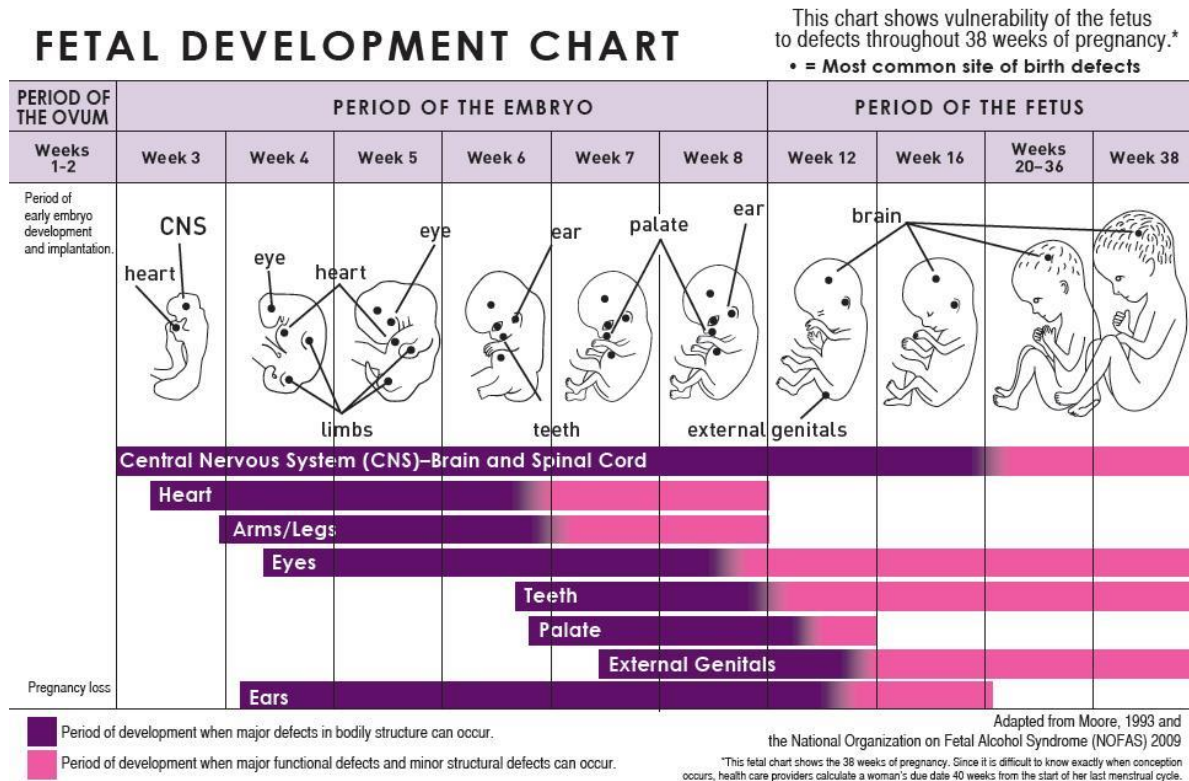
Source: Adapted from Moore, K. L., & Persaud, T. V. N. (1993). *The Developing Human: Clinically Oriented Embryology* (5th ed., p. 156). Philadelphia, PA: W.B. Saunders. and National Organization on Fetal Alcohol Syndrome (NOFAS). (2009). *Fetal Development Chart Poster*. Retrieved from http://www.nofas.org/fetal-development-chart/

Vulnerability of the fetus to defects varies during different periods of development. The purple portion of the bars represents the most sensitive periods of development, during which teratogenic effects on the sites listed can result in major defects in bodily structure.

The pink portion of the bars represents periods of development during which major functional defects and minor structural defects can occur.

A. Sensitivity throughout gestation

An estimated 95–100 billion neurons are found in the human cortex (Pakkenberg & Gundersen, 1997). Studies have shown that the nervous system develops in a discontinuous manner with periods of greater developmental activity followed by periods of relative quiescence. Development of the nervous system begins in about the third week of gestation and continues throughout gestation. Logic suggests that the presence of ethanol might have more significant effects during periods of rapid growth than during periods of relatively slow growth—if one considered only neurogenesis (birth of new neurons). During neuron development, however, multiple processes are occurring, such as migration, synapse formation, and myelination. Significant activity remains in the maturation of the nervous system throughout pregnancy that might be affected by the presence of alcohol.

Undoubtedly, the presence of alcohol in the first few weeks of gestation might result in the most devastating effects. This is because of the limited number of cells present in the embryo and the totipotency (the ability of a single cell to divide and produce all the differentiated cells in an organism) of each cell at that time. The loss or damage of even a few cells at that critical time might result in global changes in the development of organs at a later phase.

During the second and third trimesters, the tissues and organs have been largely formed. Some organs and systems, however, remain susceptible to potential damage or alteration caused by the presence of ethanol. The nervous system is one such system. Its long period of development increases its vulnerability to the teratogenic effects of alcohol and other drugs. The same is true for the eyes and ears, portions of which are extensions of the developing nervous system. Exposure to alcohol during the most sensitive periods of development might result in major structural or functional abnormalities, including FAS or an FASD depending on the extent of the effect on the system (Coles, 1994). Individuals might have cognitive and/or behavioral impairments, problems with language and/or memory, difficulty with visual-spatial learning, attention disorders, reduced reaction times (based on how quickly the brain is able to process information), and deficits in functioning, such as planning and organizing. These impairments might occur in both individuals with FAS and those with other forms of FASDs (Hunt, Streissguth, Kerr, & Olson, 1995; Janzen, Nanson, & Block, 1995; Mattson, Riley, Delis, Stern, & Jones, 1996; Streissguth, 1997; Uecker & Nadel, 1996).

Effects of drinking habits. Drinking habits might play a significant role in predicting the effects of ethanol on the developing nervous system (Abel & Hannigan, 1995). Heavy, chronic drinking is sure to affect the development of the nervous system dramatically. Binge drinking, however—that is, consuming four or more drinks on a single occasion for women—might be especially damaging (Maier & West, 2001). As stated earlier, given the complex nature of neural development (e.g., neurogenesis, migration, synapse formation), there is no real period of developmental quiescence. No period or volume of alcohol has

been deemed "safe." Therefore, any drinking might have adverse effects on development of the nervous system, regardless of frequency, amounts consumed, or the gestational trimester in which alcohol intake occurs.

B. Postnatal effects of alcohol abuse

Although much of the nervous system is formed prenatally, a significant amount of maturation occurs postnatally. Myelination and synapse formation continue through the first year of life. Alcohol exposure during this period of time has been shown to interfere with myelination resulting in alterations in motor movements (Domellöf, Fagard, Jacquet, & Rönnqvist, 2011).

Since alcohol is a depressant on the nervous system, alcohol exposure during the lactating period might be damaging to the nutritional intake of the infant. Effective suckling and nursing is reduced in infants exposed to alcohol through breast milk. Their suckle response is less effective and, because of the depressive effect of ethanol, they nurse less effectively, sometimes falling asleep more easily during nursing. The American Academy of Pediatrics (AAP) recommends that breastfeeding should occur two or more hours after alcohol use in order to minimize its concentration in the breast milk (AAP, 2012).

IV. Cellular response to alcohol exposure

Substantial research has examined the cellular responses and molecular mechanisms affected by fetal alcohol exposure (Dunty, Zucker, & Sulik, 2002; Gleason, 2001). These investigations and descriptions have been associated with one or more of the following processes during neural development.

A. Neurogenesis

As stated previously, neuron generation occurs very rapidly in the developing embryo and fetus. Through mitosis, a cell duplicates the chromosomes in its nucleus and creates two identical daughter cells. The deleterious effects of alcohol exposure on this process have been well described in both animal models and models using cultured neurons. Cell numbers in certain regions of the brain are affected, which might result in cognitive and behavioral deficits (Rupert, Miñana, Pascual, & Guerri, 2006; Miller & Spear, 2006; Olney, 2004).

B. Growth and differentiation of neurons

Newly formed neurons undergo maturation or differentiation. Associated with this differentiation is the genetic expression of appropriate neurotransmitters (communication chemicals) for synaptic function, growth, and migration of the processes (neurites) to their respective locations and migration of the cell to its appropriate location (brain or spinal cord nuclei). Each of these processes is vulnerable to the effects of ethanol exposure depending on when alcohol exposure occurs coincident with the process. As such, alcohol exposure at

any time might affect any one of the processes in various ways (Rupert et al., 2006; Joshi et al., 2006; Miller & Spear, 2006).

C. Migration

Cellular migration occurs, as does migration of the cell process, to form nerve pathways. Neuron migration takes place upon a glial cell scaffolding to reach its ultimate destination, usually among cells of similar function in a nucleus or cell layer.

Migration of the processes occurs using molecules in the membrane that follow substrates in the tissue and are supported by chemicals called nerve growth factors. The neurites are guided to their respective destinations following chemical substrates for which the neurites have an affinity. Subsequent neurites follow the first by using molecules called cell adhesion molecules (CAM) to co-locate to the appropriate destination forming a "nerve" (Bearer, 2001; Ozer, Sarioglu, & Güre, 2000; Ramanathan, Wilkemeyer, Mittal, Perides, & Charness, 1996).

D. Synaptogenesis

Once arriving at its predetermined destination, the neurite must form a synapse to function normally. The connection between two nerves, or between a nerve and another cell (such as a muscle or glandular cell), is a chemical link that allows communication between the nerve and the other cell. This is a critical junction at which various components must be present for proper operation. Again, the junction is determined by pre-programmed molecules that act as substrates to indicate the position of the synapse. Alcohol exposure during this period might disturb the various mechanisms on which normal synaptogenesis depends (Hsiao et al., 2002; Tenkova, Young, Dikranian, Labruyere, & Olney, 2003; Yanni & Lindsley, 2000).

E. Apoptosis

More nerves are formed in the brain than are actually needed. This might be to ensure correct synapse formations for critical functions. For example, neurons might be formed and reach their targets. There might, in fact, be twice as many cells reaching those targets. Only those cells forming a functional synapse on the target will be supported by nerve growth factors. The other neurons reaching that target cell will not be supported and will be discarded by a process of programmed cell death called apoptosis.

Apoptosis also might occur in cells that are needed but are erroneously "activated," through alcohol or other teratogens, to undergo cell death. Alcohol exposure, therefore, might enhance apoptosis, resulting in more extensive cell death than what was biologically programmed (Cartwright, Tessmer, & Smith, 1998; Dikranian, Qin, Labruyere, Nemmers, & Olney, 2005; Wozniak et al., 2004).

F. Plasticity

When a nerve cell or its process is damaged, such as by trauma, its ability to grow back and re-establish meaningful connections is a function of its plasticity. Most neurons are "plastic" during development; however, when maturation occurs, they are regarded as post-mitotically static and become less able to regenerate their function. Alcohol exposure during development appears to decrease the ability of the nervous system to regenerate (Choi, Allan, & Cunningham, 2005; Medina, Krahe, Coppola, & Ramoa, 2003).

V. Putative biomedical mechanisms

Pharmacologically, ethanol is a "dirty" drug. Although classified as a depressant, it might have a variety of molecular effects, rather than one specific effect. FASDs might occur because of this variety of effects. That is, there might not be any one molecular reason that alcohol exposure during development results in FASDs. Rather, it is more likely that FASDs are a result of the additive or synergistic effects of alcohol on the developing system.

Numerous scientific studies have sought to determine the biomedical mechanisms associated with FAS and other FASDs. These studies are associated with cellular and molecular investigations that are, for the most part, related to mechanisms of neural development.

A. Neuromorphological and neurotrophic effects

This category of investigations has resulted in some of the best examples of how alcohol affects developing cells and the migration of those cells and their processes. Study findings might explain many of the effects of FAS and/or FASDs (Acquaah-Mensah, Kehrer, & Leslie, 2002; Cartwright et al., 1998; Charness, Safran, & Perides, 1994; Deltour, Ang, & Duester, 1996; Gohlke, Griffith, Bartell, Lewandowski, & Faustman, 2002; Grummer, Salih, & Zachman, 2000; Guerri, Montoliu, & Renau-Piqueras, 1994; Heaton, Mitchell, Paiva, & Walker, 2000; Kelce, Ganjam, & Rudeen, 1990; Luo & Miller, 1997; McAlhany, West, & Miranda, 2000; Miller, Moony, & Middleton, 2006; Olney et al., 2002; Ozer et al., 2000; Pennington, Boyd, Kalmus, & Wilson, 1983; Poggi et al., 2003; Rudeen, 1996; Scott, Sun, & Zoeller, 1998; Scott, Zoeller, & Rudeen, 1995).

These studies have shown that alcohol has the following effects:

- Alters neurogenesis and migration of neurons, by various mechanisms, including interruption of mitosis, alteration of glial proteins serving as guiding factors, and inhibition of trophic factors that provide substrates to migrating processes
- Increases neuronal cell death and/or apoptosis by either the deleterious toxic effects of ethanol directly on the cell, or through programmed cell death
- Alters dendritic growth, resulting in losses of functionality
- Changes glial fibrillary acidic protein expression
- Alters microvascular development, resulting in localized cellular loss

- Decreases protein synthesis, causing a reduction in cell function
- Enhances free radical toxicity, causing premature death of cells
- Impairs DNA methylation, resulting in alteration of transcription in preparation for RNA expression
- Alters mRNA translation of protein synthesis
- Induces hypoxia and/or ischemia.

B. Effects on neurotransmitter receptors

Other scientific investigations have attempted to determine fetal alcohol effects on cellular/molecular function that might occur following development (Miller 2006; Olney et al., 2002; Toso et al., 2006). Examples of the effects of alcohol exposure during development on neurotransmitter receptors include:

- Up-regulation (increased sensitivity) of NMDA receptors
- Altered GABA-mediated neurotransmission
- Excess nitric oxide (NO) formation leading to glutamate-mediated cell death
- Specific apoptotic cell death in NMDA and GABA receptor systems
- Abnormal serotonergic and/or catecholaminergic system development.

VI. Genetic variants and markers

Alternate forms of the ADH gene have been demonstrated to metabolize alcohol differently (Chambers & Jones, 2002). The ADH2*3 allele of the ADH gene, for example, was demonstrated to protect against the adverse prenatal effects of alcohol among Blacks or African Americans (McCarver, Thomasson, Martier, Sokol, & Li, 1997; Stoler et al., 2002).

The protective effect of the ADH2*3 allele is believed to be associated with rapid metabolism of alcohol to acetyaldehyde, which might influence the quantity or frequency of alcohol drinking. More rapid metabolism of alcohol might also reduce the amount of alcohol the fetus is exposed to after consumption, as well as shorten the period of exposure. Supportive studies have found that women who lack the ADH2*3 allele tend to report drinking more alcohol at the time of conception, twice as much overall, and almost twice as much per occasion than those who had the allele (Viljoen et al., 2001).

This effect, however, cannot be considered proven as it has not been confirmed by other studies. It also is not clear if this polymorphism will help predict which specific alcohol-consuming women are at higher risk of having a child with an FASD.

It is generally accepted that the model of 'multi-factorial inheritance' is the best fit to explain the genetic basis of teratogens and their influence on the developing fetus. The basic premise of multi-factorial inheritance is that both genetic and environmental factors interact to have significant contributions to the phenotype. The observed pattern of multi-factorial inheritance is that of a heritable trait which does not exhibit characteristics of mono-genic (Mendelian) inheritance. The primary principles of multi-factorial inheritance include:

- Genetic variability exists, yet no uni-factorial mode of inheritance can be defined.
- Family studies indicate an increased risk for near relatives to be affected.
- The process usually involves complicated pathophysiology or morphogenetic processes.
- The process requires biologic influences of environmental factors.

The ultimate expression of multi-factorial conditions involves exceeding a biologic threshold for the ability of the organism to buffer against pathogenic outcomes. This threshold is exceeded by the acquisition of the organism of cumulative liabilities – both genetic and environmental. It is envisioned that the general population has a normative distribution of the total accumulation of liabilities – both predisposing genetic factors and damaging environmental factors. For a detailed explanation of multi-factorial inheritance and other gene-environment interactions, see the textbook *Medical genetics: An integrated approach* by Schaefer & Thompson (2014).

Alcohol-related teratogenesis follows most of the basic tenants of teratogen biology. The expression of abnormal fetal development due to the in utero exposure to ethanol is dependent on many known and probably more unknown variables. The following discussion reviews both traditional and emerging factors that have been shown to influence the expression of alcohol influenced birth defects (McCarthy & Eberhart, 2014).

A. Traditional features of teratogenic agents and their effects

It is first important to point out a few factors that are known <u>not</u> to influence teratogenic expression. First, it is known that the 'type' of alcohol is not significant. What is important is the absolute amount of ethanol consumed regardless of the vehicle. Specifically the teratogenic potential of alcohol is no less for beer or wine than for 'hard liquor.'

The timing of the exposure of alcohol influences expression. Significant exposures in the first couple of weeks post-conception will typically induce pregnancy loss if there is an effect. Exposures later in the first trimester are associated with structural congenital anomalies and the dysmorphic features characteristic of FAS. Second and third trimester exposures can be associated with pregnancy loss, brain anomalies (both macroscopic and at the cellular level), and impaired fetal growth. The pattern of drinking also influences teratogenic expression. The overall risk of teratogenic expression increases with the absolute amount of exposure—that is, increasing dosage is associated with greater effects. Likewise, the longer the time of the exposure (duration), the greater the effects. In general, binge exposures may be more significant than chronic exposures.

The teratogenic potential of any agent is dependent upon many physico-chemical properties. Ethanol has all of the right properties to make it an effective teratogen. A major factor in this regard is the ability of the agent to cross the placenta. Ethanol readily crosses the placenta as it is a small molecule – a two carbon alcohol. It is a lightly charged molecule and dissolves well in lipids (and in water).

Advances in genomic technologies have allowed for the identification of some of the genetic factors involved in teratogenesis. These factors are deemed to infer 'genetic susceptibility' to the environmental influence of the teratogens. This susceptibility can occur at many places in the biologic system that is the maternal-fetal unit. For instance the susceptibility to phenytoin in the fetal hydantoin syndrome seems to be primarily a genetic susceptibility at the fetal level (Buehler, Rao, & Finnell, 1994). However, for FASDs, it has been demonstrated that both the fetal and the maternal genome play a role in the susceptibility (Gemma, Vichi, & Testai, 2007).

Central to the understanding of the expression of a teratogenic exposure is the knowledge of the underlying pathogenic processes that are affected. While many such factors are still unknown for FASDs, many processes are known to play a role in their expression. Ethanol is primarily a cellular toxin. Any cell – fetal or not – exposed to enough ethanol will die. Much of the aberrant physiology seen in alcohol teratogenesis can be attributed simply to the overall loss of cells. The results of cellular loss are reflected in the clinical features. For instance, a decreased number of cells in the cerebral cortex results in microcephaly. Likewise, the in utero growth retardation and the correlated postnatal primordial short stature are due to an overall reduction in somatic cells. One critical factor is the overall reduction in the number of fat cells that develop in utero. Postnatally this can present as a child misdiagnosed as "failure to thrive." An understanding of normal embryology and the developmental processes in morphogenesis also correlate with an overall decreased rate of cell growth. Key phenotypic features such as the under-developed philtrum, short palpebral fissures and even abnormal dermatoglyphics are primarily due to reduced rates of cell growth and migration.

While ethanol itself is the initial teratogen, secondary differences in metabolism and elimination also influence its teratogenic effects. Polymorphisms in the genes that regulate the ADH pathway have been suggested to affect alcohol teratogenesis. Chronic exposure to ethanol may enhance or induce other pathways. In particular, one known toxic by-product is acetaldehyde, which is then further metabolized by ALDH. Reduction in the elimination of acetaldehyde is likely to also be toxic to the fetus.

Alcohol is known to have a vaso-constrictive effect. This is especially important to the maternal-fetal connection. Some of the ethanol related effects may be due to micro-vessel ischemia.

While in utero exposure to ethanol may be isolated, exposures to additional harmful agents are common. The teratogenic effects of alcohol can be accentuated or compounded by exposure to more than one agent. In fact, it is quite common for there to be more than one type of teratogenic exposure. Other agents such as cigarettes, other substances of abuse, prescribed pharmaceuticals, over the counter compounds, and even natural or homeopathic substances have the potential to be independently or synergistically teratogenic with ethanol (i.e., co-teratogens). Exposure to multiple teratogens clearly carries a higher risk; however, little research has been accomplished to define what these potential interactions might actually be.

B. Emerging concepts in the pathogenesis of alcohol-medicate teratogenesis

Over the past decade, advances in the understanding of alcohol-induced birth defects have identified a large number of potentially contributing factors. Insights into these processes are particularly exciting as some actually have the potentrial for associated therapeutic interventions.

Maternal nutrition. It has become clear that maternal nutritional factors play a large role in the process of alcohol-induced birth defects. Many maternal nutritional factors have been suggested to play a role in the occurrence and severity of FASDs. Some of these factors include:

- **Overall protein-calorie intake.** Protein-calorie malnutrition invokes a large cascade of compensatory hormonal and metabolic changes. These changes accentuate the primary mechanism of reduced cell number and growth rate (Keen et al., 2010).
- **Zinc deficiency.** Pregnancy induces a physiologic zincuresis. The zinc status of most gravid women would meet the definition of 'zinc deficiency.' Notably, zinc deficiency appears to be a definite co-teratogen with alcohol (Keen et al., 2010).
- **Cholesterol.** Cholesterol plays a major role in cell membrane structure and function. It is involved in cell signaling and hormone production. Smith-Lemli-Opitz (SLO) syndrome is a recognizable multiple anomaly syndrome caused by a metabolic defect in the terminal step of the synthesis of cholesterol. Much of the pathogenesis in SLO (including structural anomalies) is due to cholesterol deficiency. The phenotypes of SLO and FAS are noted to overlap. Ethanol is reported to affect cholesterol homeostasis (Guizzetti & Costa, 2007).
- **Vitamins.** Ethanol has been shown to result in under-expression of several vitamin-associated genes, including those related to retinoic acid, niacin, vitamin D, and folic acid (Feltes, de Faria Poloni, Nunes, & Bonatto, 2014). Folic acid is particularly interesting in that altered folate concentrations within the placenta and in the fetus may in part contribute to many of the deficits observed in FASDs.
- **Iron.** Iron deficiency seems to exacerbate prenatal alcohol effects on growth. Adequate maternal iron status has been proposed to be protective against many of the effects of alcohol teratogenesis (Rufer et al., 2012).
- **Choline.** Choline is a precursor to the neurotransmitter acetylcholine. In addition, it has been known for decades that alcohol increases choline requirements. Prenatal ethanol exposure has been shown to deplete accessible choline in the fetus (Swanson, King, Walker, & Heaton, 1995).

An extremely exciting and promising part of this body of knowledge is the potential for secondary prevention of alcohol-induced teratogenic effects. Specifically, micronutrient supplementation is theoretically protective. Potentially the prenatal supplementation of any of these compounds could ameliorate or eliminate alcohol effects. Multiple studies have been and are being conducted at different levels (Patten, Sickmann, Dyer, Innis, & Christie, 2013; Thomas, Abou, & Dominguez, 2009) but there is not yet enough evidence for the

standard supplementation of nutritional elements. Maternal nutrition clearly is a major factor in ethanol mediated teratogenesis. Anything that can be done to improve overall maternal nutritional status can only help. In the future the hope is that there will be answers to the questions "What to supplement?, When to supplement?, How much to supplement?"

Epigenetics. Epigenetics is the change in gene expression without an alteration in the DNA code itself. Tremendous advances in the understanding of the mechanisms of epigenetic processes have been made over the past 15 years. Because epigenetic regulation of gene expression does not involve coding changes, the potential for therapeutic manipulation is much great than traditional 'gene therapy.' A large body of knowledge on the epigenetic effects of prenatal alcohol exposure has emerged (Ungerer, Knezovich, & Ramsay, 2013). Prenatal alcohol exposure has been shown to alter multiple epigenetic processes, including DNA methylation, histone modifications, and ncRNA regulation.

While FASDs, by definition, are caused from the mother's use of alcohol during pregnancy, research continues to examine the effects of the male partner's alcohol use prior to conception. While it is important for the male partner to be helpful and supportive during pregnancy in order to help the mother avoid alcohol intake, paternal alcohol intake will not invoke teratogenic pathogenesis in a developing fetus. However, the potential of paternal alcohol use alternating epigenetic regulation in germ cells has been suggested as at least a possibility (Bielawski, Zaher, Svinarich, & Abel, 2002).

Other possible mechanisms of alcohol teratogenesis. Because of its generalized effects as a disrupter of normal cellular metabolism and function, ethanol can easily be shown to affect almost anything. This makes it particularly hard to sort out primary versus secondary effects. Besides those factors noted above, many other mechanisms have been purported to have a potential effect in the generation of alcohol-induced teratogenesis. Some of these include effects on intermediary metabolism, mitochondrial function, energy generation, and even free radical generation.

The ubiquitous effects of ethanol on genomic, metabolic, hormonal, and regulatory functions make it extremely difficult to tease out the major points of influence. In reality, it is likely that each pregnancy has its own unique pattern (profile) of genetic factors and susceptibilities interacting with teratogens (alcohol) and a host of environmental variables. More complex evaluations such as nodal analyses will be needed to develop a hierarchy of targets of alcohol and its devastating effects on the developing fetus.

Suggested Learning Activities

- Ask the group to draw out what happens when a drink is ingested by a pregnant woman.
- Ask participants to discuss how damage to neurons through any of these mechanisms may result in behavioral or cognitive changes.
- Assign small groups topics in this competency to further investigate and present creatively to the group. Compare and contrast results.

- Have individuals or small groups read current research articles about the biological effects of alcohol and share summaries, written and/or oral.
- Have participants discuss how maternal diet may influence genetic expression.

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Competency V: Screening, Diagnosis, and Assessment for Treatment Planning

Yasmin Senturias, MD, FAAP; David Wargowski, MD; and Roger Zoorob, MD, MPH, FAAFP

The health care student or provider will be able to screen, diagnose, and assess individuals for fetal alcohol spectrum disorders (FASDs), including infants, children, adolescents, and adults.

Learning Goals

V-A Describe the diagnostic criteria and approaches for diagnosis for each condition along the continuum of FASDs, including ND-PAE, FAS, pFAS, and ARBD.

V-B Appreciate major physical and neurobehavioral features for differential diagnosis of FASDs from other genetic and behavioral disorders as well as relevant comorbidities.

V-C Learn how to screen patients to obtain information on prenatal exposure to alcohol from patient or caregivers.

V-D Understand potential referrals, secondary conditions, risk factors, and treatment planning for individuals with FASDs.

Content Outline for Competency V

I. Fetal alcohol spectrum disorders overview and evaluation
  A. Continuum of FASDs
  B. Diagnostic criteria for each condition along the continuum of FASDs

II. Variability in presentation and range of adverse effects
  A. Physical features
  B. Neurodevelopment
  C. Presentation across the life span

III. Differential diagnosis and comorbidities

  A. Differential diagnoses for physical phenotype
  B. Differential diagnoses for neurobehavioral phenotype
  C. Comorbid diagnoses

IV. Screening and obtaining history of in utero exposure to alcohol

V. Other considerations
  A. Referrals
  B. Risk factors and concerns that may trigger evaluation for FASDs
  C. Assessment for secondary conditions and treatment planning

Also included in this section are:

- Suggested learning activities
- References

I. Fetal alcohol spectrum disorders overview and evaluation

A. Continuum of FASDs

Fetal alcohol spectrum disorders (FASDs) is an umbrella term that encompasses several diagnoses resulting from in utero exposure to alcohol. It is not intended as a clinical diagnosis, but rather a collective term for more specific diagnoses. Diagnoses included under this umbrella are: neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE); fetal alcohol syndrome (FAS); partial FAS (pFAS); and alcohol-related birth defects (ARBD). Most clinicians are aware of FAS, the most involved condition within the spectrum for surviving children with both physical and neurodevelopmental features. However, FAS does not encompass the full complement of diagnoses under the umbrella of FASDs. Specific criteria exist for diagnosis of FAS, and more recently for ND-PAE; however, research continues to provide more clinical clarity for all conditions within the spectrum.

B. Diagnostic criteria for each condition along the continuum of FASDs

The broad categories for diagnostic consideration [in utero exposure to alcohol, central nervous system (CNS) abnormalities, dsymorphic facial features, and growth restriction] have not changed since the phenomena was first described in the U.S. medical literature by Jones, Smith, Ulleland, and Streissguth (1973). In 1996, the Institute of Medicine (IOM) published a report (Stratton, Howe, & Battaglia, 1996) that outlined criteria for the specific diagnoses under the umbrella of FASDs.[1] Significant research and clinical knowledge since that time has refined those criteria, for individual diagnoses, although a single unifying diagnostic scheme for all diagnoses is not currently available. It is expected that criteria for all diagnoses within the continuum of FASDs will continue to be developed and refined with periodic updating, including development of an overall scheme.

Criteria presented here represent either the most recent iteration and/or clinically relevant criteria for specific diagnoses. These diagnostic criteria are intended to guide the diagnostician while using his or her clinical experience or judgement, rather than function as strict operational definitions. As always, a patient's individual situation will need to be taken into account when making a diagnostic decision. For a comprehensive pediatric checklist designed to facilitate the identification, diagnosis, and referral of a child with an FASD, see: https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Documents/Provider_Checklist.pdf

Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE). In most clinical settings and for most families, the primary concern is the effect prenatal alcohol exposure (PAE) has on the brain, or CNS, and how this will manifest in a child's development, behavior, and mental functioning. For most children with FASDs, behavioral issues will be the presenting concern. Neurobehavioral disorder associated with prenatal alcohol exposure (ND-

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[1] The umbrella term of FASDs was adopted by the field in 2006 and is not used in the IOM report.

PAE) [2] is the appropriate mental health diagnosis among the continuum of FASDs that addresses these concerns (Olson, 2015). It is delineated in the Diagnostic and Statistical Manual (DSM-5) of the American Psychiatric Association (APA, 2013). In addition to prenatal exposure to alcohol, criteria for ND-PAE include impairments in ***neurocognition, self-regulation,*** and two areas of ***adaptive functioning***, presented in Figure 5.1.

As noted in Figure 5.1, neurocognitive impairment may be manifest as reduced global intellectual or developmental performance or more specific impairments such as executive functioning (e.g., poor planning and organization, inflexibility, difficulty with behavioral inhibition), impaired learning (e.g., lower academic achievement than expected for intellectual level; specific learning disability), poor memory skills (e.g., problems remembering information learned recently, repeatedly making the same mistakes, difficulty remembering lengthy verbal instructions), or problems with visual spatial reasoning (e.g., disorganized or poorly planned drawings or constructions, problems differentiating left from right). Impairment in self-regulation may be manifested as difficulty with mood regulation (e.g., mood lability, negative affect or irritability, frequent behavioral outbursts), attention deficits (e.g., difficulty shifting attention, difficulty sustaining mental effort), or impulse control problems (e.g., difficulty waiting turn, difficulty complying with rules). Finally, adaptive functioning impairment may be observed for communication skills (e.g., delayed acquisition of language, difficulty understanding spoken language), social communication or interactions (e.g., overly friendly with strangers, difficulty reading social cues, difficulty understanding social consequences), daily living skills (e.g., delayed toileting, feeding, or bathing; difficulty managing daily schedule), and/or motor skills (e.g., poor fine motor development, delayed attainment of gross motor milestones or ongoing deficits in gross motor function, deficits in coordination and balance) (Kable, et al., in press; Doyle & Mattson, 2015).

An important component for diagnosing ND-PAE is establishing that the individual was "exposed to alcohol at any time during gestation, including prior to pregnancy recognition and the exposure level was more than minimal." Minimal intake is defined in the DSM-5 as no more than 13 drinks per month and no more than 2 drinks per occasion. Exposure may occur in any 30-day period of pregnancy and need not occur during each month of pregnancy. Confirmation of gestational exposure to alcohol may be obtained from maternal self-report of alcohol use in pregnancy, medical or other records, or clinical observation.

Evaluation for the other diagnostic features can be done through the ongoing surveillance and monitoring of CNS function as a routine medical practice or a targeted assessment. Information about CNS abnormalities may be obtained by report, observation, and/or standardized testing.

Because impairment in neurocognition, self-regulation, and adaptive functioning are common to many disorders, it is important to keep in mind that it is impairment of the specific constellation

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[2] ND-PAE updates the Institute of Medicine term alcohol-related neurodevelopmental disorder (ARND), which lacked diagnostic specificity. However, the term ARND may have utility in research settings, with further clarification from additional data or in very specific cases assessed by an FASD expert.

of criteria outlined by the DSM-5 that constitute the diagnosis (see Hagan et al., 2015, for more detailed review). For example, although global delay or intellectual impairment may meet criteria, for more specific impairment in neurocognition, individuals with ND-PAE (and other FASDs) tend to have trouble with visual-motor skills that can cascade into academic problems with math knowledge and skills, including grapho-motor skills. Learning and memory problems often manifest as difficulty remembering recently learned or mastered information, for example morning routines. Self-regulation may take the form of an attention-deficit/hyperactivity disorder (ADHD) diagnosis, however it also may manifest as sleep problems, mood liability, or impulse control. Finally, impairments in adaptive function may occur in communication, social, daily living, or motor skills. The important concept is that the manifestation of the broad diagnostic categories and constellation of these specific categories constitute the diagnosis of ND-PAE. For additional information on neurobehavioral problems manifested across FASDs see Competency VI. For more information on differential diagnosis of ND-PAE see Hagen, et al., 2015, and Kable, et al., in press.

In the DSM-5 schema, ND-PAE is listed as an example of Other Specified Neurobehavioral Disorder (code 315.8) as well as a condition for further study (APA, 2013)[3]. In DSM-5, neurobehavioral disorders have qualifiers such as onset age and/or severity scales, as well as other qualifiers that can be "associated with a known medical or genetic condition or environmental factor." Health care professionals are able to document factors that may have contributed to the disorder's etiology and also how those factors affect a child on a clinical basis. Fetal alcohol exposure is listed as one of the medical conditions, even in the absence of FAS (APA, 2013).

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[3] Note that for Other Specified Neurobehavioral Disorder (code 315.8) the word "neurodevelopment", rather than "neurobehavioral" is used. This is an artifact of the DSM development process and the term used in Section III (i.e., "neurobehavioral") supersedes when applying the criteria (Olson, 2015).

Figure 5.1.   DSM-5 Proposed Criteria for Neurobehavioral Disorder Associated With Prenatal Alcohol Exposure (ND-PAE)

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PRIMARY DIAGNOSTIC CRITERIA

All 4 criteria must be present for the diagnosis of ND-PAE

- **Impaired neurocognitive functioning** as indicated by at least one of the following: 1) impairment in *global intellectual performance* (i.e., IQ/standard score of 70 or below or comprehensive developmental assessment), 2) impairment in *executive functioning*, 3) impairment in *learning*, 4) *memory* impairment, 5) impairment in *visual-spatial* reasoning.

- **Impaired self-regulation** as indicated by at least one or more of the following: 1) impairment in *mood or behavioral* regulation, 2) *attention* deficit(s), 3) impairment in *impulse control*.

- **Impaired adaptive functioning** as manifested by TWO or more of the following, one of which must be in the areas of communication or social skills: 1) *Communication* deficit, 2) impairment in *social communication and interaction*, 3) impairment in *daily living skills*, 4) impairment in *motor skills*.

- **More than minimal exposure to alcohol during gestation**, defined as at *least 13 or more drinks within a month* (i.e., 30 day period) with no more than 2 drinks per occasion, at any point during pregnancy, including prior to pregnancy recognition.

ADDITIONAL CONSIDERATIONS

- Onset of impairments (neurocognitive, self-regulation and adaptive functioning) are evident in childhood, by current report, observation or history.

- Behaviors and/or deficits cause clinically significant distress or functional impairments in social, academic, occupational, or other important areas of functioning.

- The disorder is not better explained by other causes such as postnatal use of a substances (e.g., a medication, alcohol, or other drugs), a general medical condition (e.g., traumatic brain injury, delirium, dementia), another known teratogen (e.g., fetal hydantoin syndrome), a genetic condition (e.g., Williams syndrome, Down syndrome, Cornelia de Lange syndrome), or environmental neglect.

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Source: Adapted from American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Publishing.

Fetal alcohol syndrome (FAS). People with FAS present with abnormalities in both physical and CNS features with the backdrop of alcohol exposure in utero. Although FAS is the most widely known condition along the continuum of FASDs, most individuals affected by in utero exposure to alcohol will not have the facial features and/or growth problems of FAS and thus are more likely to receive a diagnosis of ND-PAE (May, 2011). In many cases, however, a comorbid diagnosis of ND-PAE also may be appropriate for an individual diagnosed with FAS. Criteria for FAS described by the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect[4]

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[4] Fetal alcohol effects (FAE) is an outdated term for adverse birth outcomes that could be proven to be related to alcohol exposure in utero, but did not meet the diagnostic criteria for FAS. The term was never meant to be used as a diagnostic term or with individual patients.

is presented in Figure 5.2 (Bertrand et al., 2004). These criteria represent those put forth by the IOM with the addition of functional criteria for CNS abnormalities.

Figure 5.2.   Diagnostic Criteria for Fetal Alcohol Syndrome

Facial dysmorphia
Based on racial norms, individual exhibits all three characteristic facial features:
- Smooth philtrum (University of Washington Lip-Philtrum Guide rank 4 or 5)
- Thin vermillion border (University of Washington Lip-Philtrum Guide rank 4 or 5)
- Small palpebral fissures (at or below 10th percentile)

Growth problems
Confirmed prenatal or postnatal height or weight, or both, at or below the 10th percentile, documented at any one point in time (adjusted for age, sex, gestational age, and race or ethnicity).

Central nervous system abnormalities
  I. Structural
      A. Head circumference (OFC) at or below the 10th percentile adjusted for age and sex.
      B. Clinically significant brain abnormalities observable through imaging.

  II. Neurological
    Neurological problems not due to a postnatal insult or fever, or other soft neurological signs outside normal limits.

  III. Functional
    Performance substantially below that expected for an individual's age, schooling, or circumstances, as evidenced by:
      A. Global cognitive or intellectual deficits representing multiple domains of deficit (or significant developmental delay in younger children) with performance below the 3rd percentile (2 standard deviations below the mean for standardized testing) or
      B. Functional deficits below the 16th percentile (1 standard deviation below the mean for standardized testing) in at least three of the following domains:
        1. cognitive or developmental deficits or discrepancies
        2. executive functioning deficits
        3. motor functioning delays
        4. problems with attention or hyperactivity
        5. social skills
        6. other such as sensory problems, pragmatic language problems, memory deficits, etc.

Maternal Alcohol Exposure
   I.   Confirmed prenatal alcohol exposure
   II. Unknown prenatal alcohol exposure

Criteria for FAS Diagnosis
Requires all three of the following findings:
   1. Documentation of all three facial abnormalities (smooth philtrum, thin vermillion border, and small palpebral fissures)
   2. Documentation of growth deficits
   3. Documentation of CNS abnormality

Source: Bertrand, J., Floyd, R. L., Weber, M. K., O'Connor, M. J., Riley, E. P., Johnson, K. A., & Cohen, D. E. (2004). *National task force on fetal alcohol syndrome and fetal alcohol effect. Fetal alcohol syndrome: Guidelines for referral and diagnosis*. Atlanta, GA: Centers for Disease Control and Prevention.

Physical features of FAS include specific dysmorphic facial features and growth retardation. Features consistent with CNS abnormality include microcephaly, other structural anomalies, or functional deficits. Specific features are described below with dysmorphic facial features illustrated in Figure 5.3.

Dysmorphic facial features
Dysmorphic facial features are a reflection of abnormal brain growth of the fetus (Aase, 1990; Foroud et al., 2012). Although a variety of dysmorphic facial features can occur with in utero exposure to alcohol, the generally accepted three cardinal features that distinguish FAS from other exposure syndromes or genetic disorders include:

- Smooth philtrum (University of Washington Lip-Philtrum Guide[5] rank 4 or 5)
- Thin upper lip [vermillion border] (University of Washington Lip-Philtrum Guide rank 4 or 5)
- Small palpebral fissures (at or below 10th percentile).

Frequently associated dysmorphic features that may also be seen in individuals with FASDs (but are not required for diagnosis) include: hypoplastic nails, short fifth digits, clinodactyly of fifth fingers, pectus carinatum/excavatum, camptodactyly, "hockey stick" palmar creases, refractive errors, low nasal bridge, epicanthal folds, micognathia, or "railroad track" ears. Additional features that have been noted are listed in Jones (2006).

Detection and confirmation of major and minor structural anomalies is part of any general physical examination (Aase, 1990; Douzgou et al., 2012). To more specifically evaluate the facial criteria for FAS, a clear plastic ruler with blunt edges is recommended to measure the palpebral fissure length. Measurement should be from the inner to outer corners of the eye (endocanthion to exocanthion) which is compared to a normogram that accounts for variations due to age. For assessment of the upper lip and philtrum, the University of Washington Lip-Philtrum Guides (Astley, 2004b) are recommended. The Lip-Philtrum Guide is a 5-point pictorial scale that measures the smoothness of the philtrum and the thinness of the upper lip. There are two Guides currently in use: Guide 1 is for Caucasians and all other races with lips like Caucasians; Guide 2 is for African American and all races with lips as full as African Americans. The guide should be placed next to the patient's face and the most similar Rank assigned. A Rank 4 or Rank 5 for lip or philtrum indicate the feature is consistent with a FAS, pFAS, or ARBD diagnosis. For further training on the diagnosis of facial criteria see the AAP FASD Toolkit https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/Diagnostic-Tools.aspx. In addition to the cardinal features of FASDs, any other dysmorphic features should be documented in the patient record.

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[5] The University of Washington has developed a very useful lip-philtrum guide depicting 5 points along a continuum of normal to smooth philtrum/thin vermilion border, available at: http://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm.

Growth restriction
The second criterion for FAS diagnosis is confirmed prenatal or postnatal height or weight, or both, at or below the 10th percentile, documented at any one point in time (adjusted for age, sex, gestational age, and race or ethnicity).

Central nervous system (CNS) abnormalities
Diagnostic criteria for CNS abnormalities include structural, neurologic, and functional components.

- <u>Structural</u>**:** Head circumference at or below the 10th percentile adjusted for age and sex. Clinically significant brain abnormalities observable through imaging (reduction in size or change in the shape of the corpus callosum, cerebellum, or basal ganglia) (Bertrand et al., 2004).

- <u>Neurologic</u>**:** Neurologic problems such as seizures not due to postnatal insult or fever, or other soft neurologic signs outside normal limits.

- <u>Functional</u>**:** Performance substantially below that expected for an individual's age, schooling, or circumstances, as evidenced by: global cognitive or intellectual deficits representing multiple domains of deficit (or significant developmental delay in younger children) with performance below the third percentile (two standard deviations below the mean for standardized testing); or functional deficits below the 16th percentile (one standard deviation below the mean for standardized testing). Particular attention should be given to evaluation in the domains identified as criteria for ND-PAE, specifically: neurocognition, self-regulation, and adaptive functioning.

Prenatal exposure to alcohol
Although confirmation of maternal use of alcohol during pregnancy is desirable, it is not always available. Situations such as adoption, foster care, or failure of mother to disclose information can hinder the diagnostic process. Because the combination of cardinal facial features are considered quite distinctive to in utero exposure, documentation of maternal consumption during pregnancy is generally preferred but not required for the FAS diagnosis.

Figure 5.3.   Dysmorphic Facial Features Associated with Fetal Alcohol Syndrome

Small palpebral fissures

Smooth philtrum

Thin upper lip/ Vermillion border
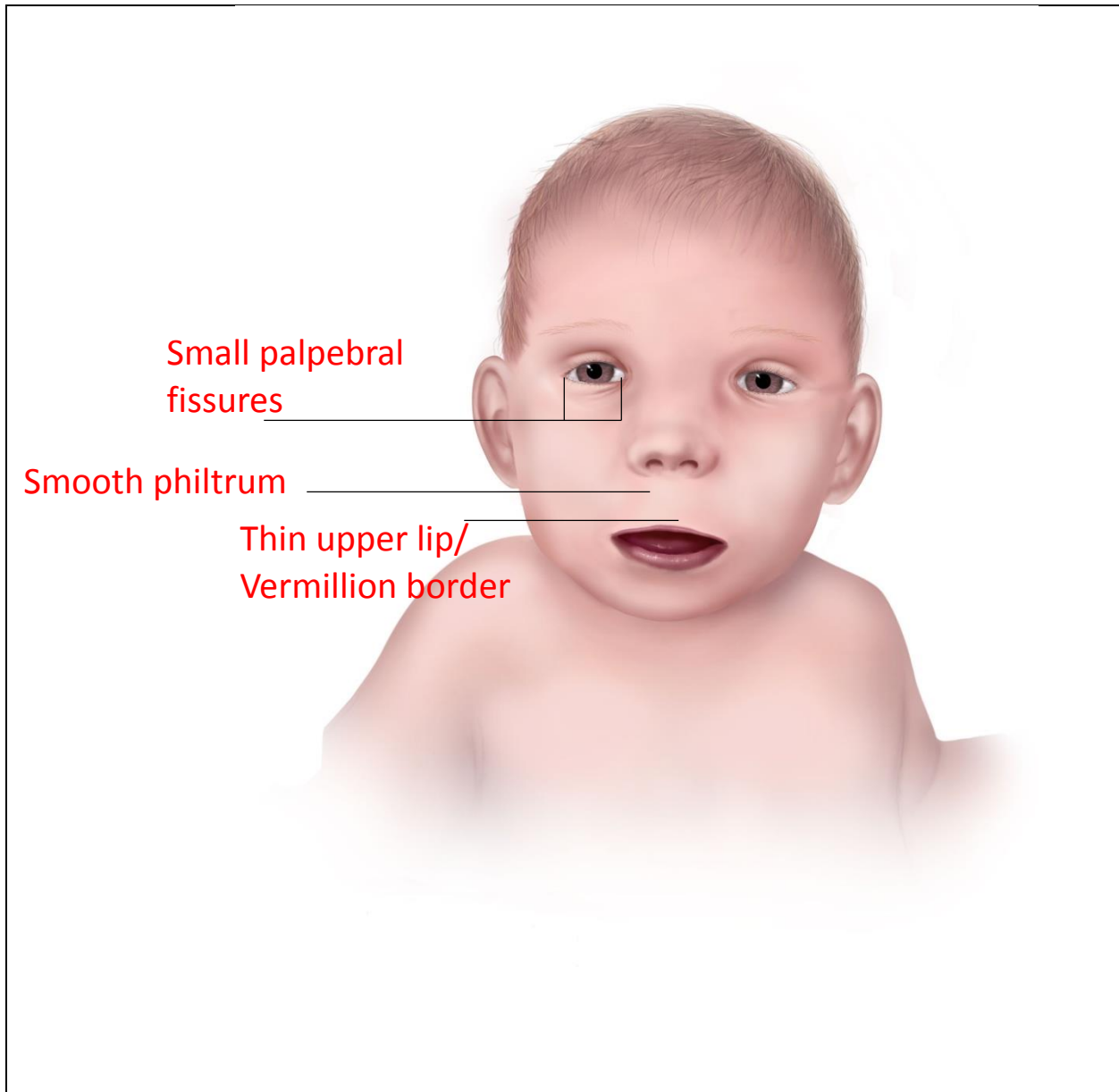
Source: Bertrand, J. & Dang, E. (2012). Fetal alcohol spectrum disorders: Review of teratogenicity, diagnosis and treatment issues. In: D. Hollar (Ed.) *Handbook of children with special health care needs* (pp.231-258). New York, NY: Springer.

Partial fetal alcohol syndrome (pFAS). In 2005, Hoyme and his colleagues published a revision of the IOM criteria that provided additional guidance for diagnosis of partial FAS. This diagnosis is most appropriate for patients that show several characteristics of FAS, but do not meet full criteria for that diagnosis. A comorbid diagnosis of ND-PAE also may be appropriate. Criteria for pFAS (Hoyme et al., 2005) include:

- Evidence of a characteristic pattern of facial anomalies as well as either growth retardation, CNS abnormalities, or cognitive abnormalities that are characteristic of full blown FAS. The facial anomalies must include 2 of the 3 cardinal facial characteristics of FAS (palpebral fissures $\leq 10^{th}$ centile, thin vermilion border, and smooth philtrum).

- In addition, pFAS diagnosis requires one or more of the other characteristics: prenatal or postnatal growth retardation ($\leq 10^{th}$ centile) in height or weight; small head circumference ($\leq 10^{th}$ centile);

  OR evidence of a complex pattern of behavioral or cognitive abnormalities inconsistent with developmental level and unexplainable by genetic composition, family background, or environment alone.

- Like FAS, confirmation of maternal alcohol consumption during pregnancy is preferable. However, like FAS it is not required and confirmation/non confirmation may be included as a qualifier to the diagnosis.

Alcohol-related birth defects (ARBD). A rarely used diagnosis within the spectrum is alcohol-related birth defects (ARBD). This diagnosis is intended to capture those individuals with congenital anomalies, malformations, and dysplasias due to in utero exposure to alcohol. In the 2005 revision by Hoyme et al., dysmorphic facial features were added as criteria along with confirmed in utero exposure to alcohol. Structural birth defects and anomalies listed include:

- Cardiac anomalies: atrial septal defects, aberrant great vessels, ventricular septal defects, conotruncal heart defects

- Skeletal anomalies: radioulnar synostosis, vertebral segmentation defects, large joint contractures, scoliosis

- Renal anomalies: aplastic/hypoplastic/dysplastic kidneys, "horseshoe" kidneys/ureteral duplications

- Ocular anomalies: strabismus, ptosis, retinal vascular anomalies, optic nerve hypoplasia; conductive hearing loss, neurosensory hearing loss

- Dysmorphic facial features (2 out of 3 required): short palpebral fissures ($\leq 10^{th}$ percentile); thin vermilion border of the upper lip (score 4 or 5 with the lip/philtrum guide); and smooth philtrum (score 4 or 5 with the lip/philtrum guide). In addition, congenital structural defects must be present in one or more of the above categories,

including malformations and dysplasias (note: if the patient displays dysmorphic facial features only, two or more features must be present).

II. Variability in presentation and range of adverse effects

As with most developmental disorders and conditions, the number and severity of negative effects can range from subtle to serious. The heterogeneity of presentation for individuals with prenatal alcohol exposure is greater than many conditions due to variability in the specific interaction of dose, timing, pattern (chronic vs. binge), and postnatal environment experienced. Variability occurs for both physical and neurodevelopmental features.

A. Physical features

As noted in the previous section, in addition to the three cardinal dysmorphic features, additional associated features are frequently observed. These generally include minor anomalies of the ears, hands, and eyes, although other dysmorphic features may be present. The severity of any individual features may range. This is most notable with the philtrum, ranging from completely indistinct to near normal. Likewise, growth retardation can range from slight to severe. Growth problems can vary across development: with some individuals only having prenatal growth problems and being born small for gestational age; others may have normal birth weight but slow postnatal growth lasting through childhood; and some experience both prenatal and postnatal growth issues. Finally, growth problems may also be associated with nutritional factors, even for a person with prenatal alcohol exposure, which complicates the diagnostic picture.

B. Neurodevelopment

The greatest variability among individuals with FASDs is seen in neurodevelopment, again most likely due to timing and extent of in utero exposure to alcohol as well as genetic predispositions. For neurocognitive deficits it important to note that most individuals with FASDs achieve IQ scores within the normal range and do not meet criteria for intellectual disability. While a few individuals with FASDs (including those with full FAS) will score in the high to above average range in IQ, about 86% of individuals score in the low average to average range (Streissguth, Barr, Kogan, & Bookstein, 1996; Streissguth et al, 2004). Beyond general intellectual functioning, individuals with FASDs are likely to present with impairment in specific cognitive domains, including executive functioning, learning and memory, or spatial reasoning (Mattson, Crocker, & Nguyen, 2011; Mattson et al, 2013; Substance Abuse and Mental Health Services Administration, 2014). These deficits may be seen even when IQ is within normal limits. Although standardized testing may be informative, it is important to remember that the key point in determining neurocognitive impairment is whether the individual is functioning as expected for their chronological age (or corrected age for children younger than 24 months) and/or family situation. Math difficulties are common in individuals with FASDs, often out of proportion to overall IQ. Parents of children with FASDs frequently report memory impairments that include problems remembering information learned recently or skills previously mastered, difficulty learning from experience such as repeatedly making the same mistakes, and problems

remembering lengthy verbal instructions (Crocker, Vaurio, Riley, & Mattson, 2011). These memory issues often create a mistaken assumption that a child is being defiant or willfully disobeying rather than having genuine difficulty; the "can't vs. won't" error. Finally, individuals with FASDs may show marked impairment in visual construction and visual motor integration, affecting handwriting and daily living skills (e.g., tying shoe laces).

Self-regulatory deficits include emotional dysregulation and attention deficits. The most common self-regulation impairment for individuals with in utero exposure to alcohol is attention deficit, which can range from mild to severe. ADHD is a common co-diagnosis with individuals with FASDs. Identification and categorizing problems related to alcohol exposure, as opposed to ADHD of other etiologies or as co-diagnoses, can be challenging. It has been shown that children with prenatal alcohol exposure can have attention problems associated with encoding information and shifting attention while children diagnosed with ADHD (without prenatal alcohol exposure) have difficulty with tasks requiring focus and sustained attention (Coles et al., 1997), suggesting different attentional profiles for the two groups.

Another area of self-regulatory deficits that is problematic for individuals with FASDs is sleep. Approximately 82% of individuals with FASDs report sleep disturbances (Jan et al., 2010). Again, this problem can range from mild to severe and from chronic to episodic. Within this domain, sensory processing deficits are common and may contribute to sleep problems (Wengel, Hanlon-Dearman, & Fjeldsted, 2011).

Adaptive skills are the ability to independently perform developmentally expected tasks associated with daily living, such as self-care, communication, and social skills. These skills have been found to be impaired in children with FASDs (Streissguth et al., 2004; Kable & Coles, 2004; Whaley, O'Connor, & Gunderson, 2001) regardless of informant (e.g., parent, teacher, foster caregiver). Also, using the Vineland Adaptive Behavior Scales, it has been shown that prenatally exposed children exhibit maladaptive behaviors, such as failure to consider the consequences of their actions, difficulty understanding social cues, indiscriminant social behavior, and difficulty communicating in social contexts. They also lack understanding of appropriate social behavior, an impairment that appears to be independent of verbal skills (Shonfeld, Paley, Frankel, & O'Connor, 2006; Thomas, Kelly, Mattson, & Riley, 1998).

C. Presentation across the life span

Although the majority of patients assessed for FASDs are children, these diagnoses can be established at any age (Foroud et al., 2012). This is particularly important because neurodevelopmental deficits often worsen over time, especially if not addressed through intervention. Facial dysmorphia and growth deficits may become less pronounced with time; however, the cardinal morphologic traits (short palpebral fissures, smooth philtrum, thin upper lip) can still be detected even after puberty (Chudley, Kilgour, Cranston, & Edwards, 2007). Although the approach to the diagnostic assessment in later years is fundamentally the same as it is with young children, it can present significant challenges, including the temporal distance from the exposure history and perinatal course. In some cases, information about the

early childhood environment and experiences, childhood health, and growth and development is also lacking, insufficient, or of questionable accuracy. In such situations extra effort is required to obtain available and relevant records. Assessment beyond childhood does provide some advantages, including the ability to better define cognitive, neurobehavioral, and other functional CNS deficits. Secondary disabilities become apparent during these stages as well (Streissguth et al., 2004). Other elements of the assessment can be easily performed at any age. Growth deficits often persist especially in males. Since most cranial growth occurs during early childhood, microcephaly present at that time also tends to persist (Spohr, Willms, & Steinhausen, 2007).

III. Differential diagnosis and comorbidities

Evaluation or input from a multidisciplinary team is an efficient and effective approach to diagnosis of a condition along the continuum of FASDs (Manning & Hoyme, 2007). As is true of most congenital anomaly syndromes, FAS and the spectrum of effects of PAE are not defined by any single feature. Each individual characteristic, whether it falls under the category of growth impairment, dysmorphology, or neurobehavioral deficits, can occur in other genetic or teratogenic syndromes, developmental disorders, or neurobehavioral disorders. Specificity of the diagnosis comes from identifying a constellation of features that are attributable to PAE, while simultaneously recognizing any characteristics that are not attributable to PAE and therefore indicative of either a different or a superimposed diagnosis. Several syndromes commonly cited as alternative diagnostic considerations are described in Figure 5.4. It is important to emphasize that under-diagnosis of FASDs continues to be a much greater problem than misdiagnosis (Chasnoff, Wells, & King, 2015; CDC, 2015). In the majority of cases, individuals who satisfy established diagnostic criteria can be given a diagnosis along the continuum of FASDs with confidence.

A.   Differential Diagnoses for physical phenotype

Although the FAS facial phenotype is distinct, individual craniofacial features seen in FAS may be characteristic of other disorders. Disorders that should be considered in the differential for FAS are listed in Figure 5.4. In addition, overlapping and differentiating features are presented. Likewise, growth restriction occurs for several disorders or may be due to nutritional factors, neglect, or other factors such as medication side effects. However, diagnosis of an FASD should be considered for all patients who are below the 10th percentile in height, weight/length, or height-to-weight ratio. Finally, as would be expected, neurobehavioral features of FAS may be seen in several genetic syndromes. For example, attention problems and poor social communication skills are features of Fragile X. These syndromes also are included in Figure 5.4.

Figure 5.4.   Differential diagnosis of craniofacial features found in fetal alcohol syndrome

Syndromes	Overlapping Features	Difference from FAS
Fetal hydantoin	Hypertelorism, flat nasal bridge	Short nose, bowed upper lip
Maternal PKU	Epicanthal folds, short palpebral fissures, long smooth philtrum, thin vermillion border, small upturned nose	Prominent glabella, rounded facies
Cornelia De Lange	Long philtrum, thin upper lip, upturned nose, depressed nasal bridge	Synophrys, long eyelashes, downturned corners of mouth, high arched palate, short limbs
Aarskog	Small upturned nose, hypertelorism, broad philtrum, maxillary hypoplasia	Rounded face, downslanting palpebral fissures, rounded face, widow's peak, dental eruption problems
Toluene embryopathy	Short palpebral fissures, smooth philtrum, thin vermillion border, midface hypoplasia	Large anterior fontanel, micrognathia, downturned corners of mouth, bifrontal narrowing, ear anomalies
Bloom	Prenatal growth restriction, flat midface, microcephaly	Telangiectatic erythema of face, skin pigmentary abnormalities, tendency to develop malignancies
Dubowitz	Prenatal growth deficiency, microcephaly, hypertelorism, short palpebral fissures	Infantile eczema, high-pitched hoarse cry, limb anomalies, variable ptosis, cryptorchidism
Williams	Short palpebral fissures, upturned nostrils, long philtrum, flat nasal bridge, epicanthal folds	lower lip and periorbital fullness, stellate irises, connective tissue disorder, hoarse voice
Noonan	Hypertelorism, flat nasal bridge, epicanthal folds	Downslanting palpebral fissures, ptosis of eyes, wide mouth, keratoconus, webbed neck, low nuchal hairline, pectus excavatum, pulmonic stenosis
Floating-Harbor	Smooth philtrum, thin lips	Broad bulbous nose, wide columella, prominent eyes in infancy and deep-set eyes in older children
Opitz	Hypertelorism, smooth philtrum, short palpebral fissures, anteverted nostrils, mild to moderate intellectual disability	Cranial asymmetry, widow's peak, grooving of nasal tip, intellectual disability is usually associated with structural CNS deficits
Geleophysic dysplasia	Thin vermillion border, long smooth philtrum, short nose, anteverted nares	Round full face, gradual coarsening of face with growth
Fetal valproate	Epicanthal folds, long philtrum with thin vermillion border, upturned nostrils, telecanthus	High forehead, narrow bifrontal diameter, infraorbital groove or crease

Miller-Dieker	Thin vermillion border, small nose with anteverted nostrils	Vertical ridging and furrowing in central forehead, bitemporal narrowing, variable high forehead
FG	Short palpebral fissures, Hypertelorism	Large anterior fontanel, prominent lower lip, prominent forehead, frontal hair upsweep
Trisomy 18	Short palpebral fissures	Prominent occiput, narrow bifrontal diameter, small oral opening
Fragile X	ADHD, poor social communication	Hand flapping, poor eye contact, autistic behaviors, severe intellectual disability
22q11 deletion	Short palpebral fissures, deficient malar area, learning disabilities with low normal to mild intellectual disability	Prominent nose with squared nasal root, velopharyngeal insufficiency, T-cell dysfunction, parathyroid problems, conotruncal heart defects, psychiatric issues (delusions, paranoia)
Oculodentodigital	Short palpebral fissures, epicanthal folds	Hypoplastic alae nasi, microphthalmos, microcornea, orbital hypotelorism with normal inner canthal distance
Turner	Small stature, epicanthal folds, agenesis of corpus callosum, low normal IQ, difficulties with math and problem-solving, relative weakness in non-verbal skills, poor social communication, hearing impairment	Only females, webbed neck, narrow palate, abnormal karyotype
16p11 deletion	ADHD, variable intellectual disability, autistic behaviors	Deep-set eyes, open mouth due to low muscle tone, PDA
10p deletion	Variable intellectual disability, hyperactivity	Hypoparathyroidism, deafness and renal anomalies and cardiac abnormalities

Source: Adapted from: Bertrand, J., Floyd, R. L., Weber, M. K., O'Connor, M. J., Riley, E. P., Johnson, K. A., & Cohen, D. E. (2004). *National task force on fetal alcohol syndrome and fetal alcohol effect. Fetal alcohol syndrome: Guidelines for referral and diagnosis*. Atlanta, GA: Centers for Disease Control and Prevention. And Senturias, Y. & Asamoah A. (2014). Fetal alcohol spectrum disorders: Guidance for recognition, diagnosis, differential diagnoses and referral. *Current Problems in Pediatric and Adolescent Healthcare, 44*(4) 88-95.

B. Differential diagnoses for neurobehavioral phenotype

Differential diagnosis for the neurobehavioral phenotype can be particularly challenging due to substantial overlap of some diagnostic features with other disabilities. Further, the disorder does not always present the same way in all children due to differences in timing and amount of prenatal alcohol exposure as well as difference in genetic predispositions or postnatal environment. As with physical features, the severity of presentation as well as the constellation of neurobehavioral characteristics will vary greatly from child to child. A 2011 panel of experts convened by the Centers for Disease Control and Prevention (CDC) in collaboration with the

National Institute on Alcohol Abuse and Alcoholism (NIAAA) concluded that scientific data supported the three major areas of impairment—neurocognition, self-regulation, and adaptive functioning—along with evidence of in utero exposure to alcohol as a basis for diagnostic criteria. Figure 5.5 summarizes the differences between neurobehavioral syndromes that can look like FASDs. The table contrasts these other conditions with ND-PAE since it currently is the most specifically delineated neurobehavioral aspect of the spectrum.

Figure 5.5.   Differential Diagnosis for ND-PAE

	Neurocognitive	Behavioral Regulation	Adaptive Functioning	Key Differential from ND-PAE
Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE) (formerly referred to as alcohol-related neurodevelopmental disorder (ARND)	Intellectual skills may be in the intellectually deficient range for some but not most. Deficits in executive functioning skills, learning, memory, and/or visual spatial reasoning are common.	Self-regulation impairments may take the form of poor mood or behavioral regulations skills, attention deficits, and poor impulse control. They are best characterized by arousal dysfunction involving slower gating of incoming stimulation and reduced capacity to inhibit attending to distracting stimuli. They respond to simplification of sensory input (fewer distracters and slower presentation).	Adaptive functioning skills often fall below that of their overall IQs and often there are declines in their skills as they grow older relative to their peers. This may result in the standard scores being lower as they age. They often have impairments in the pragmatic communication skills, are socially disinhibited, and have poor quality motor skills or coordination with the latter	Not applicable

			being a greater deficit in young rather than older children.	
Global developmental delay/intellectual disability (ID)	Children with global developmental delay by definition have impairments in multiple domains of functioning (i.e., cognitive and motor functioning) Intellectual skills are in the intellectually deficient range by definition. This often involves IQ score below 70 on most standardized tests. Other cognitive skills general consistent with overall IQ.	Behavioral regulation skills are variable depending on the nature of the disorder causing the developmental delays or intellectual disability and the extent of the brain damage.	Adaptive functioning skills are also in the low or deficient range and are general stable over the lifetime relative to peers and consistent with their levels of intellectual functioning.	▪ Overall development or IQ is often not delayed or intellectually impaired in ND-PAE. Early developmental problems in ND-PAE are often detected in motor functioning and/or quality of motor functioning. The cognitive deficits may not be detectable in the first year of life on measures of early childhood development. ▪ Children with ND-PAE have behavioral regulation deficits and those with ID may not. ▪ Children with ND-PAE have adaptive skills below IQ and/or declining with age.
Attention-deficit / hyperactivity disorder (ADHD)	Overall IQ is typically within normal limits	ADHD is characterized by problems with	Adaptive skill deficits are often present in	▪ The extent of neurocognitive impairment is often

	but often individuals with ADHD have learning difficulties and may be academic underachievers.	sustaining attention and being impulsive or hyperactive. The disorder may be seen as being chronically under-aroused and individuals respond to stimulant medications and increases in arousal (exercise/movement or increasing arousal level of learning material).	untreated individuals with ADHD but with appropriate supports and medication may be age appropriate.	greater in children with ND-PAE than those with ADHD. ▪ Children with ND-PAE also demonstrate declines in adaptive skills with age. ▪ Children with ND-PAE deteriorate under conditions of high arousal but often improve in children with AD-HD
Autism spectrum disorder (ASD)	Intellectual skills vary with some being in the severely intellectual deficient range and other functioning within normal limits or gifted.	Child is easily over aroused and benefits from reducing sensory input during instruction.	Adaptive skills are often deficient but typically they have relative deficits in the social and communication skills as compared to their independent living skills.	▪ Children with ASD are characterized by being socially withdrawn and children with ND-PAE are more likely to be socially disinhibited. ▪ In ASD, there is significant lack of social and emotional reciprocity whereas in ND-PAE, the problem is socially inappropriate behavior that relates to their lack of cause and effect reasoning, slow and ineffective processing of what people say during conversation and

			lack of visual spatial skills that govern their ability to put their body at an appropriate distance from another. ▪ Children with autism generally have stereotypies that are odd or very repetitive in nature, which are not as common or may not at all be seen in some children with ND PAE.
Early trauma exposure/post traumatic stress disorder (PTSD)	Intellectual skills would typically be within normal limits. For many, there may be deficits associated with environmental deprivation but when removed from the adverse environment, young children often demonstrate dramatic gains in developmental functioning. Older children may have more	Children with PTSD often have arousal dysfunction. They may have sleep problems, be anxious, and easily startle. They often have difficulty focusing on tasks and sustaining mental effort. Often these deficits are the result of anxiety and/or intrusive thoughts.	Adaptive skills are often below that of their cognitive functioning skills. Some may have deficits associated with cues associated with the traumatic event. For many, these deficits may be associated with environmental deprivation but when removed from the adverse environment	▪ Young children with PTSD will demonstrate quicker recovery of function in cognitive skills if placed into a stable, nurturing environment. ▪ Children with PTSD may have more anxiety type symptoms. ▪ Children with PTSD may have difficulties with forming positive relationships with caregivers. ▪ The extent of the cognitive impairment is typically not as

	persistent cognitive deficits, particularly in the area of memory functioning. The length of exposure to trauma and environmental deprivation typically relates to the extent of impairment.		and placed into a positive, nurturing environment, young children often demonstrate dramatic gains in developmental functioning. Older children may have more persistent adaptive deficits. The length of exposure to trauma and environmental deprivation typically relates to the extent of impairment.	great but may be in extreme abusive cases.
Bipolar disorder (BD)	Intellectual skills would typically be within normal limits.	The disorder is characterized by cyclic periods of depression and mania. During episodes of depression, the child's affect may be flat and he/she may lack interest in his/her preferred activities. During episodes of mania, the child may be extremely active	Adaptive skills deficits may or may not be present but often are the result of the mood disturbance interfering with learning age appropriate adaptive skills or being able to carry-out the skill.	▪ Children with BD typically do not have the same magnitude of cognitive impairment.

		and have difficulty organizing or regulating their thought patterns. Often children do not have the full pattern of cycling in the early stages of the disorder and may only become easily irritated or have significant mood lability.		

Source: Adapted from Hagan, J.F., Balachova, T., Bertrand, J., Chasnoff, I. J., Dang, E. P., Fernandez-Baca, D. … Zubler, J. (2015). Special Article: Identification, diagnosis and management of neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE). Manuscript submitted for publication.

C. Comorbid diagnoses

Specifying co-occurring disorders is also important to obtain a complete picture of the child's strengths and weaknesses for shaping an appropriate treatment or referral course. Although ADHD is the most common comorbid condition with FASDs, other frequent comorbid conditions include:
- Bi-polar disorder
- Communication disorder
- Depression/anxiety
- Intellectual disability
- Features of autism
- Learning disability
- Oppositional defiant disorder
- Post-traumatic stress disorder
- Reactive attachment disorder
- Sleep abnormalities
- Social skill deficits
- Specific phobias
- Other conditions, such as enuresis, encopresis, and eating disorders may present depending on the child.

Because of the categorical nature in which FASDs are delineated, an additional diagnosis within the spectrum may be appropriate. For example, an individual with both facial dysmorphia and growth restriction as well as neurocognitive impairment, self-regulation problems, adaptive problems, and a history of in utero exposure to alcohol could receive diagnoses of FAS (or pFAS) and ND-PAE.

IV. Screening and obtaining history of in utero exposure to alcohol

Inquiring about consumption of alcohol can be the most difficult aspect of determining if a diagnosis of a condition along the continuum of FASDs is appropriate. Conversations about alcohol use may be uncomfortable for the clinician and the patient (or informant), especially when those conversations concern use during pregnancy and involve a clinician speaking with the birth mother. Further, in many situations the necessary information may not be available (e.g., older children or adults, adopted individuals, maternal death). However, ***obtaining information about prenatal exposures, especially alcohol, is the best practice of medicine***.

Most individuals being assessed for FASDs will be pediatric patients. Typically the physician will be talking with the birth mother. There are several known techniques that can facilitate this conversation:

- Questions about alcohol use during pregnancy embedded within a series of questions about general pregnancy topics may be less threating. Topics such as nutrition during pregnancy and other potential exposures (e.g., medications) should be queried and documented. Documentation of exposures (or confirmed non-exposures) may be useful in later evaluations.
- Because of the stigma associated with alcohol use during pregnancy, asking patients about pre-pregnancy drinking may improve accuracy of the screening.
- Questions presented as routine and asked in a non-judgmental manner typically produce the most reliable and valid information. For example, asking "How much alcohol did you consume while pregnant?" rather than "You didn't drink while pregnant, did you?" Questions that require "yes/no" answers (e.g., "Do you drink alcohol?") should be avoided since they may limit or end the conversation.
- Use of a standard script for question often eases physician discomfort and provides reassurance to the caregiver. A revision of the AAP toolkit for FASDs suggests the following sequence of questions to obtain information about prenatal exposure to alcohol for postnatal patients and the newest edition of *Bright Futures* also contains this suggestion (Bax, Geurts, & Balachova, 2015; Hagan, Shaw & Duncan, in press):
  - o "How often do you drink beer, wine, or liquor in your household?" (Continue for any response other than "never")
  - o "In the 3 months before you knew you were pregnant, how many times did you have 4 or more drinks in a day?"
  - o "During the pregnancy, how many times did you have 4 or more drinks in a day?"

    These questions should be asked at: 1) prenatal visits; 2) in the newborn period; 3) at the time of adoption; and 4) for new patients.

For assessments of older children, adolescents, and adults obtaining information about prenatal exposure will be difficult. However, asking about use of alcohol in the home, by both mother and father, may facilitate a discussion. Obtaining previous records also may be a source of information.

V. Other considerations

A. Referrals

As noted in the American Academy of Pediatrics (AAP) FASD Expert Panel algorithm for identification and referral, two main types of referral may be indicated: 1) multidisciplinary clinic specializing in developmental disabilities and/or FASDs; and 2) individual subspecialists.

Because FASDs are a spectrum of disorders with very heterogenetic presentation of both physical and developmental features, a multidisciplinary team approach can be very helpful. However, access to such resource may not be available in all areas. For FASDs, multidisciplinary teams generally consist of a geneticist, neuropsychologist, and social worker (at a minimum). Additional specialties may include occupational, speech or physical therapists, addition specialist, or education consultant. Final diagnosis, along with treatment planning, is usually done in a case conference format where each professional presents their findings and the group determines diagnosis and next steps collectively.

In addition to referral to a multidisciplinary clinic, or if one is not accessible, referral to individual specialists may be warranted. Other subspecialty assessments to consider based on findings include:

- Cardiology for congenital heart defects
- Developmental-behavioral pediatrics for assessment of developmental disability differential diagnosis or comorbidities
- Medical genetics for further diagnostic assessment if diagnosis is still in question
  - Consideration of differential diagnoses (see Figure 5.4) and relevant assessment (e.g., 22q11.2 FISH)
- Neurology for seizures or other neurologic findings
- Ophthalmology (visual deficits, optic nerve hypoplasia)
- Orthopedics for musculoskeletal including spinal abnormalities Otolaryngology for frequent ear infection (note: individuals with FASDs in general have reduced immune function resulting in frequent ear and respiratory infections)
- Plastic surgery for cleft palate

An important part of the referral process for teams and specialists is documentation of findings and concerns, since not all criteria for an FASD (e.g., ND-PAE) may present in a single visit or have emerged. Sometimes, symptoms of ND-PAE may not be apparent until school age; when prenatal alcohol exposure is documented, these deficits can be understood in the right context. For example, executive function deficits often do not become apparent until school age, so documentation of prenatal exposure to alcohol would put those deficits in proper context. Physicians should record answers in the child's medical chart documenting the level of prenatal alcohol exposure, as well as any early concerns indicative of ND-PAE (e.g., self-regulation as evidenced by sleep problems or prolonged tantrums). Frequent developmental screening is essential, with early referral to developmental specialists if concerns are identified. An algorithm for the evaluation of FAS/FASDs in the medical home can be found within the freely

downloadable AAP FASD Toolkit. See http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/Algorithm-for-Evaluation.aspx

B. Risk factors and concerns that may trigger evaluation for FASDs

Several risk factors that should prompt a full evaluation for an FASD diagnosis include:

- Having a sibling with FAS or an FASD
- Family history of substance abuse
- History of being in foster/adoptive care or involvement with child protective services
- Previous diagnosis of ADHD with poor response to medication/therapies.

C. Assessment for secondary conditions and treatment planning

Secondary disabilities are the resultant problems or disorders that occur when the primary disabilities in children with FASDs are not addressed. Although secondary disabilities are covered in more detail in Competency VI, knowledge of them and preliminary assessment are important parts of the diagnostic assessment. Knowledge of secondary disabilities can inform or guide treatment planning and monitoring. Secondary disabilities frequently experienced by individuals with FASDs include:

- School drop out
- Difficulty finding and/or maintaining employment
- Trouble with the law (both as perpetrator and victim)
- Unstable or dependent living situations
- Inappropriate/indiscriminate sexual behavior
- Naïveté with susceptibility to negative influences or scams/scapegoating

The AAP FASD toolkit provides a chart of commonly used testing instruments across cognitive and behavioral domains that may assist in identification of secondary conditions and/or areas in need of intervention, adaptation or other services (See http://dredf.org/special_education/Assesments_chart.pdf).

Suggested Learning Activities

- Review AAP FASD Toolkit: www.aap.org/fasd
- Review AAP FASD PediaLink course, found within the AAP FASD Toolkit.
- View podcasts on FASDs from the Great Lakes FASD Regional Training Center (University of Wisconsin): https://www.youtube.com/watch?v=RiLo_9Hd1II&feature=relmfu
- Review interview with Dr. Kenneth Lyons Jones at https://www.youtube.com/watch?v=xOuEH05ooqs

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Competency VI: Treatment Across the Life Span for Persons with Fetal Alcohol Spectrum Disorders

Leigh Tenkku Lepper, PhD, MPH; Georgiana Wilton, PhD; Joy Doll, OTD; Yasmin Senturias, MD, FAAP; Kathleen Mitchell, MHS, LCADC; and Joanne Weinberg, PhD

The health care student or provider will be able to provide long-term case management for persons with FASDs.

Learning Goals

VI-A: Describe developmental and functional concerns for individuals with FASDs and their families across the life span.

VI-B: Explain various treatment approaches.

VI-C: Explain support services and resources for families and providers

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Content Outline for Competency VI

I. Concerns across the life span

   A. Infants
   B. Toddlers and preschoolers
   C. School-age children
   D. Adolescents and teens
   E. Adults

II. Providers and approaches to treatment for FASDs

   A. Medical, pharmaceutical, and therapeutic considerations

   B. Behavioral and educational interventions
   C. Mental health
   D. Primary and secondary disabilities

III. Support services and resources

   A. Disability services
   B. Parenting strategies
   C. Resources

Also included in this section are:

- Suggested learning activities
- References

I. Concerns across the life span

Fetal alcohol spectrum disorders (FASDs) occur as a direct result of maternal alcohol use during pregnancy. Alcohol is a neurobehavioral teratogen that results in lifelong problems with learning and behavior due to the brain damage caused by prenatal alcohol exposure. Challenges associated with disabilities that are not addressed early not only persist, but also might become more severe and result in additional disabilities or problems as an individual ages. As with any family that has a child with a disability, stressors and complications should be addressed for the entire family. Families affected by FASDs often have even more complex problems than families with other disabilities (Streissguth et al., 2004). Beyond addressing disabilities, due to the cognitive vulnerabilities of individuals with FASDs, families often experience challenges in individuals with FASDs exhibiting inappropriate social behaviors as well as navigating the legal system.

To best understand the developmental disabilities associated with prenatal alcohol exposure, it is important to have a basic understanding of developmental processes and how these processes might be altered. Typical, or normal, infant and preschool development is established by the accomplishment of particular milestones at particular ages in a standard sequence (Brownell & Kopp, 2010). For example, for typical motor development, infants begin to roll over at about 3 months, sit assisted at about 5 months, sit unassisted at 6 months, crawl at 7 to 8 months, cruise (walk while holding on) at 9 months, walk at 11 to 12 months, and run smoothly at around 14 months. This is considered developing on schedule. It is important to note that children develop at different rates and slight deviations are not necessarily a concern. In older children and adolescents, development is said to be typical if the individual is learning at the same rate as other children of similar age and background (Kessen, 1999). (For developmental milestones checklists see http://www.cdc.gov/ncbddd/actearly/milestones/index.html)

Developmental disabilities are defined when children: (a) have a slowed rate of development but the sequence of development is within normal limits (i.e., delayed development); or (b) achieve skills in a non-routine sequence or manner (i.e., different or scattered development). It is important to note that these two concepts are not necessarily mutually exclusive in any one child but, on the whole, characterize the general types of developmental disabilities.

In regards to delayed development, young children or infants who are not meeting milestones on time are said to have developmental delay (American Psychiatric Association, 2013, p. 41). Older children who are learning new material at a significantly slower rate than their peers are considered to have an intellectual developmental disorder (also referred to as intellectual disability). For example, a child with a generalized intellectual disability might learn language, reading, and math skills, but mastering each of these skills might take years rather than the typical weeks or months.

Different or scattered development proceeds in an atypical sequence: a child uses an unusual pathway to develop skills, or skills develop unevenly across domains (Hodapp, Griffin, Burke, & Fisher, 2011). This latter path of development often results in "peaks and valleys" of strengths and weaknesses, which very much describes individuals with FASDs (Streissguth et al., 2004).

Overall, basic language skills (vocabulary, syntax) are considered areas of strength of individuals with FASDs. In contrast, visual spatial skills are an area of weakness that can lead to significant deficits in knowledge and math-related skills. Another type of "scatter" demonstrated by individuals with FASDs occurs even within domains (Coles, Kable, Dent, & Lee, 2004; Kable & Coles, 2004). For example, although a young child may have strong vocabulary and syntax skills, yet be impaired in other social aspects of language such as understanding social boundaries, reading social cues, and relating to peers (O'Connor & Paley, 2009). These variations exist because of the damage to the brain at the time of the fetal brain development when it was exposed to alcohol (Kalberg et al., 2006; O'Leary et al., 2010).

The core disabilities that individuals with FASDs often experience include attention problems, memory deficits, executive functioning impairments, neurocognitive delays and impairments, motor delays, and inconsistent social skills, all of which are brain-based deficits (Kalberg et al., 2006). Some disabilities associated with FASDs might be overlooked in infancy and toddlerhood. However, as a child grows older and expectations increase, his or her disabilities usually become more apparent. Families and caregivers raising children and youth with FASDs have cited needs that resulted in a policy recommendation by SAMHSA's FASD Center for Excellence (Ryan, Bonnett, & Gass, 2006). Practitioners who treat or provide case management for individuals with FASDs and their families might need to make referrals to a variety of specialists throughout the individual's life span.

Across the life span, several protective factors have been associated with improved functioning for individuals with FASDs: stable nurturing care giving, early diagnosis, absence of violence, stable home placements, and eligibility for social and educational services (i.e., special education). Conversely, risk factors for poor outcomes also have been identified, including multiple caregiving placements, early or continued exposure to violence, and failure to qualify for disability services (Streissguth et al., 2004).

A. Infants

Infants with FASDs often have sensory and regulatory problems (Kully-Martens, Denys, Treit, Tamana, & Rasmussen, 2012; Fjeldsted & Hanlon-Dearman, 2009). Issues such as poor sleep-wake cycles, poor weight gain, irritability, failure to thrive, and nursing difficulties are reported frequently. Hypotonia, also known as low muscle tone where a child is often labeled as 'floppy', and fine motor problems (e.g., weak grasp) are also reported (Jones, 2006). Physical and occupational therapy or generalized early intervention can be very beneficial. Additionally, infants with FASDs often have poor immune function and may experience multiple bouts of otitis media (i.e., ear infections) and upper respiratory infections (Sliwowksa, Zhang, & Weinberg, 2006; Sekhar & Vyas, 2012). Because the spectrum of issues related to infants with FASDs is broad and can be relatively nonspecific, infants with known or suspected prenatal alcohol exposure should be closely monitored and evaluated regularly.

B. Toddlers and preschoolers

Diagnosis before the age of 6 has been shown to be a protective factor for children with FASDs (Olson & Montague, 2011), since it allows them to participate in early intervention services that can prepare them for school. Unfortunately, although disruptive behaviors may begin to emerge at this stage of development, diagnosis of conditions along the continuum of FASDs is often not initiated or completed until children enter school (Olson, Jirikowic, Kartin, & Astley, 2007) when behavioral deficits and difficulties may be better defined.

Developmental delays will occur in children differently depending upon when the child was exposed to alcohol in utero. According to Olson et al., (2007), children ages 0 to 3 vary based on their prenatal alcohol exposure with approximately 25% presenting within developmental norms, 33% showing mild developmental delays, and 33% showing significant delays or a diagnosis of FAS. Other children may not be identified as delayed or at risk during toddlerhood when executive functioning and working memory is still developing.

Common delays related to prenatal alcohol exposure include fine and gross motor challenges (O'Leary, 2004). Due to damage by prenatal alcohol exposure to the cerebellum, children with FASDs may be viewed as clumsy or prone to accidents. Children with FASDs benefit from the engagement in play activities that promote gross motor development, including activities like jumping, hopscotch, wheel barrowing, playing with balls, and riding a tricycle (Kalberg et al., 2006). Children with FASDs may also benefit from physical therapy to enhance balance and coordination skills.

Typically developing toddlers are prone to challenging behaviors at this age as they learn their way in the world (see Figure 6.1). Children with FASDs may present as impulsive and more easily frustrated than an average toddler. Some may face challenges with eating and have preferences towards certain foods or textures of foods. This can often be due to sensory issues related to FASDs (Carr, Agnihotri, & Keightley, 2010). Parents may need to introduce foods multiple times to ensure a healthy diet since children with FASDs can be underweight to begin with and have growth deficits. A typically developing child needs to try a new food 12-15 times, so children with FASDs may need even more attempts (Koponen, Kalland, & Autti-Rämö, 2009). Referrals to professionals who aid in feeding issues for children with disabilities, including occupational therapists and speech language pathologists, may be vital at this age.

Establishing and maintaining a good sleep routine may also be a significant challenge at this age, one that can span throughout childhood. Sleep deprivation is not only stressful on a family, it can exacerbate mental health issues (Chen, Olson, Picciano, Starr, & Owens, 2012). Strategies to establish good sleep patterns should start as early as possible with an identified and consistent bedtime and wake up time. A clear bedtime routine followed nightly can help. Children at this age may benefit from a visual schedule of the bedtime routine. Parents and caregivers should also ensure the sleeping environment is appropriate for encouraging sleep (e.g., have blackout curtains and very few toys and books that may distract the child from sleep). At this age, children can become very visually stimulated so muting the environment may help promote sleep and the development of healthy sleep patterns.

Sensory processing disorder (SPD) is closely associated with FASDs (Abele-Webster, Magill-Evans, & Pei, 2012). Its impact on activities of daily living and development can be substantial (Fjeldsted & Hanlon-Dearman, 2009). A child with sensory issues faces challenges with sleeping, eating, dressing, bathing, and sometimes even the most mundane task of riding in a car. Caregivers should note when children exhibit sensory defensiveness (e.g., a strong reaction against a food or the feelings of certain textures like a tag in a piece of clothing or a certain smell, finding lighting overwhelming, especially florescent lighting) or sensory seeking behavior (e.g., the child wants to touch certain textures or pushes and pulls others with too much intensity while lacking awareness of their touch). Families can address these issues by removing tags from clothing and other environmental modifications like reducing glaring lights to reduce the incidence of meltdowns. Toddlers and preschoolers with FASDs can gain in their developmental milestones with a supportive home environment and/or a preschool program catered to their needs (Tanner-Halverson, 1997). Referrals to occupational therapy professionals who can assess the child's sensory issues and develop a sensory diet are important steps if sensory issues are noted.

At this age, children with FASDs may exhibit signs of reactive attachment disorder (RAD), defined as poor attachment with caregivers. RAD is common in children with FASDs who have experienced an unstable home environment early in their life (O'Malley, 2003). It is a disorder mostly identified in young children and includes behaviors where the child is withdrawn and not apt to engage in normal social interactions with caregivers and peers. Children with RAD are often loners and are not easily comforted by caregivers due to poor attachment (American Academy of Child and Adolescent Psychiatry, 2012). Children with FASDs are at-risk for developing RAD as a secondary condition based on their living conditions. However, with a stable home environment, RAD can be prevented or appropriately addressed. Caregivers should look for signs of RAD, assure the child that the environment is safe, work to create a bond, and seek intervention as needed. Counseling and support groups may also help.

Children at this age benefit from routine and this is especially true for children with FASDs (Paley & O'Connor, 2009). Caregivers should work to establish routines for the morning, meals, and bedtime. Daily activities should be done in a specific order and caregivers should help reiterate the routines through verbal discussion, written or pictorial aids, and action. Caregivers should establish and maintain a consistent time each day for bedtime to aid in establishing healthy sleep routines. Simple instructions and limiting choices for children with FASDs is important. When offering choices, caregivers should start with few choice options to help a child with an FASD not get overwhelmed, confused or frustrated. Storytelling and coaching is important when activities deviate from the routine such as physician or family visits. Social skills training should begin at this age and can help children with transitions. A healthy developing child can exhibit behavior issues when routine changes occur or a lack of routine exists so it is important to remember this should be expected in all children at this age (Doll, 2013).

Caregivers and practitioners can focus on the child's strengths by engaging in positive and strength-based parenting. Caregivers who advocate and have knowledge about FASDs have been shown to be effective caregivers and strong supports for children with FASDs (Olson &

Montague, 2011). Several studies have identified that caregivers with internal versus external locus of control resulted in better outcomes and less stress in day to day management of children with FASDs (Wilton, 2003; Tenkku Lepper, Morgan, Salas, Olson, & Grant, 2014). Mental health issues commonly associated with FASDs may begin to emerge even in toddlerhood so caregivers should be aware of potential mental health issues and have children screened routinely.

Figure 6.1.   Brain-Based Deficits of FASDs on Daily Life
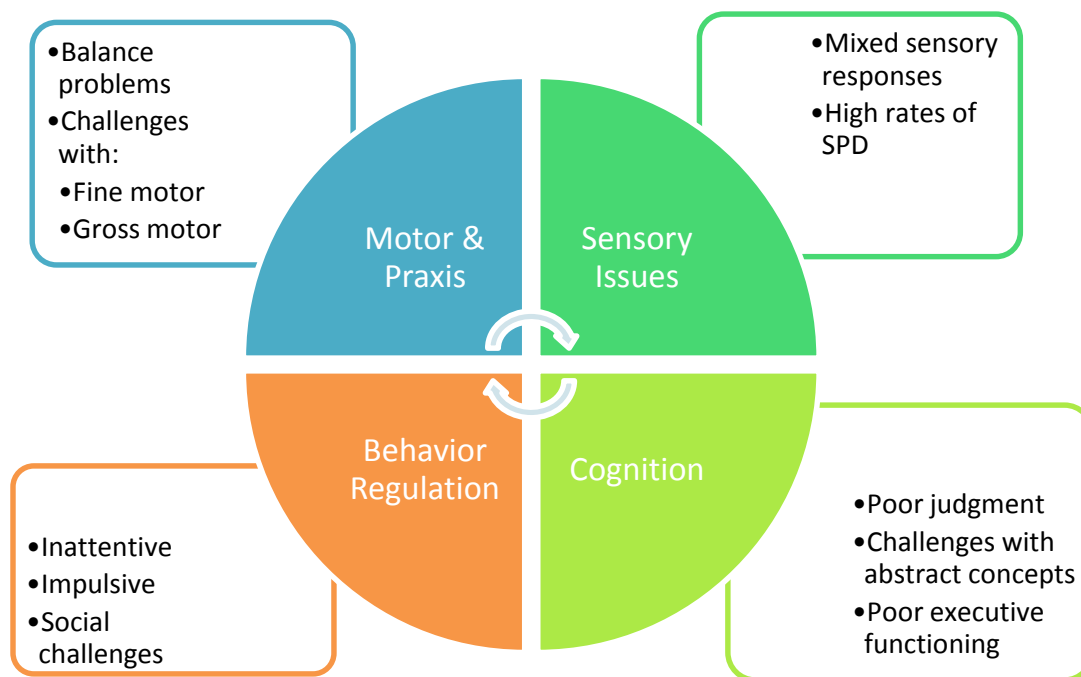
Source: Doll, J. D. (2013). The role of occupational therapy with fetal alcohol spectrum disorder (FASD). Retrieved from http://www.heartlandcenters.slu.edu/mrfastc/ot/

C. School-age children

School-age children with FASDs present their own unique set of challenges, particularly within the educational system. Since children of this age spend most of their time in school, addressing issues in this context is important for the management and quality of life of children with FASDs. This may be impacted by the neurocognitive deficits, challenges in self-regulation, and deficits in adaptive skills common to FASDs. While the majority of individuals exposed to alcohol in utero do not have significant intellectual disability (IQ below 70 with concomitant adaptive skill deficits), children with FASDs can still have global or specific deficits. The mean IQ of children with FASDs, as determined in various studies, is in the 70s to 80s (Streissguth et al., 2004; Mattson, Schoenfeld, & Riley, 2001; Mattson, Crocker, & Nguyen, 2011) and only 13% of those with FASDs would qualify for services under mild mental disability/intellectual disability. Lower IQs alone, in the absence of intellectual disability, can lead to struggles in

school. Yet children with FASDs who have IQs within the normal range (90-110) can still have academic struggles that translate into a higher risk of disrupted school experiences—especially if they do not receive the appropriate educational interventions (Mattson et al., 2011).

Attention problems are particularly common complaints during early and middle school years. Reports often include difficulty sitting in class, problems with encoding information, trouble shifting task, poor impulse control, difficulty learning, attention disorders, and often problems with sleep. As learning becomes more abstract and less concrete, executive functioning deficits become more apparent. Two areas where such executive function problems manifest are difficulty understanding cause-and-effect relations and difficulty learning from experience. These, along with self-regulatory difficulties, can lead to problems with behavior (temper tantrums, outbursts, etc.) as well as social difficulties (Kable & Coles, 2004).

Visual-spatial abilities and math skills are also areas of weakness for children with FASDs (Bertrand et al., 2004; Kable & Coles, 2004). In fact, deficits in these domains are one of the earliest and most robust findings for this population (Bertrand et al., 2004; Streissguth et al., 2004). These two domains are likely developmentally related, and problems in one affect the other. Studies show that individuals with FASDs on average score 5 points or more lower on tests of Performance IQ compared to their scores for tests of Verbal IQ (Schonfeld, Mattson, Lang, Delis, & Riley, 2001). Further, deficits in visual perception, visual memory, visual-motor integration (i.e., drawing and writing), and spatial memory have been reported by many investigators (Kable & Coles, 2004). Early visual-spatial deficits and weaknesses have been related to poor performance on arithmetic achievement tests (Coles et al., 2004; Kable, Coles, & Taddeo, 2007).

All these deficits may impact adaptive skills for daily living and affect social skills. Unlike their peers, children with FASDs often display difficulties understanding social boundaries, reading social cues, and relating to peers (Kully-Martens et al., 2012). Resulting behaviors can cause problems in developing friends in their own social group and/or put the child at risk of being abused or bullied. Children with FASDs are at high risk for victimization and do not readily understand stranger safety (Kully-Martens et al., 2012).

School evaluation, including neuropsychological assessment, should be requested for the child who has known prenatal alcohol exposure and is struggling academically. Such testing should include developmental, behavioral, and learning components. Difficulties and deficits for children with FASDs that can make learning challenging can occur in a variety of neurocognitive domains including executive function, abstract reasoning, and processing speed. Since not every child with an FASD presents with similar problems, evaluation can help school staff understand each child's unique difficulties and educational needs. In light of the DSM-5 definition of neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE), assessment of adaptive functioning may be warranted and could lead to possible increased access to services.

Deficits in neurocognitive domains, adaptive functioning, and self-regulation can lead to the development of secondary disabilities, such as disruption of school, criminal activity, and mental health problems. However, protective factors identified by Streissguth et al. (2004) appear to

reduce the rates of secondary disabilities: living in a nurturing and stable home, being diagnosed before the age of 6 years, and never having experienced violence.

D. Adolescents and teens

The cognitive, behavioral, and functioning problems associated with FASDs during the school-age years may become magnified during adolescence, especially for children without supportive services. The onset of puberty, increased complexity of social understanding, and underlying cognitive difficulties put teens with FASDs at very high risk for new or ongoing mental health issues. They can be prone to mood disorders, anxiety, depression, or a combination. These youth often struggle with developing personal or social boundaries and may be easily led into dangerous situations. Some students with FASDs experience behavioral issues that might draw negative attention and as a result become socially isolated. Impulsivity and poor judgment can make it difficult to achieve independence and to accomplish successes that their peers are experiencing, such as dating, obtaining a driver's license, or just "fitting in." All of these issues create low self-esteem leading to a difficult adulthood. Adolescents with FASDs are at greater risk than adolescents without FASDs of developing substance abuse problems (Streissguth et al., 2004), possibly as a coping mechanism, as a result of peer pressure, or due to increased genetic susceptibility.

A particularly difficult aspect for youth and young adults with FASDs is the "hidden" nature of the disorder and its specific disabilities. This is especially true for individuals without a correct FAS diagnosis or a late diagnosis of any condition along the continuum of FASDs. Often, because of the inconsistent nature of strengths and weaknesses, individuals with FASDs can give the impression of being more capable than they really are, understanding things they really do not, or having mastered material that has been forgotten. Again, this aspect of FASDs puts affected individuals at high risk for mental illness and secondary disabilities (Fryer, McGee, Matt, Riley, & Mattson, 2007; Mattson et al., 2011). In order to avoid the development of secondary disabilities, it is important to emphasize early identification and intervention for promotion of the best possible outcomes.

E. Adults

With support, many adults with FASDs can live relatively independent lives. Because these adults have unique strengths, talents, and challenges, their supportive needs will vary tremendously. However, some adults may appear more capable than they are, showing significant limitations in some areas while having strengths in others.

Adults with FASDs may have deficits in cognitive, behavioral, and adaptive domains as described in previous sections that can severely limit their ability to integrate into a community without significant supports (Clark, Minnes, Lutke & Ouellette-Kuntz, 2008). Psychosocial dysfunction has been documented (O'Connor & Paley, 2009) and an increased risk for mental health concerns has been reported (Streissguth et al., 2004). There are, however, many additional risk factors that should be considered when providing services to adults with FASDs. Adults with effects from prenatal alcohol exposure are at increased risk for risky drinking (Baer,

Sampson, Barr, Connor, & Streissguth, 2003), and women have been reported to have a poorer quality of life and experience increased psychiatric distress (Grant, Huggins, Connor, & Streissguth, 2005). Unfortunately, by adulthood many services may no longer be available and need to be provided by family and friends (Clark et al., 2008).

Community integration is a critical aspect of independence, and researchers have examined specific features that are important for success, including vocational, educational, and social opportunities; access to health care and social services; and personal independence (Clark et al., 2008). To increase service and support options, there are several federally-funded programs that may be appropriate: Social Security, Vocational Rehabilitation, and Aging and Disability Resource Centers. (See Section III, Support Services and Resources, in this chapter for more information.)

Advocacy is the key to accessing and maintaining services (Ryan et al., 2006). Typically this advocacy falls primarily on family members, but through the services identified above, in addition to other local programs, adults with FASDs have access to more support opportunities than have existed in the past. As recognition continues to grow and needs continue to be identified, support opportunities will hopefully increase as well.

II. Providers and approaches to treatment for FASDs

Assisting families that are living with FASDs can be a complex task depending upon the number and severity of the deficits. Critical elements of referral considerations include, but are not limited to, medical, clinical, therapeutic, and educational interventions. Many families and providers are experimenting with nontraditional and alternative methods of interventions. Research is currently underway to investigate successful interventions for individuals with FASDs and their families.

A. Medical, pharmaceutical, and therapeutic considerations

Children, adolescents, and adults with FASDs have all the same health and medical concerns as the general population, including well-baby care, vaccinations, good nutrition, exercise, hygiene, and basic medical care. In addition, primary care providers (PCP) can help with identification, diagnosis, and management of FASDs in the medical home while also providing referrals and anticipatory guidance for the families of children with FASDs. They can be instrumental in the early recognition of conditions along the continuum of FASDs when addressing parental concerns of poor growth and development. Primary care providers can also assist parents with ensuring the child's safety. They can help the family make decisions such as whether or not a child needs residential or therapeutic services. Finally, referrals from PCPs are critical in integrating people with FASDs into the greater medical system (Loock, Conry, Cook, Chudley, & Rosales, 2005). For individuals with FASDs, additional concerns specific to the disorder must be monitored and addressed either by a PCP or through referral and consultation with a team of specialists. Following are some issues both noted in the scientific literature and gleaned from the combined clinical wisdom of the authors.

Medical considerations.

Role of primary care clinician

The primary care clinician is crucial in the identification, diagnosis, and management of FASDs within the medical home. Some pediatric clinicians feel confident to diagnose FAS based on the Institute of Medicine (IOM) recommendations (Stratton, Howe, & Battaglia, 1996), the *FAS Guidelines for Referral and Diagnosis* (Bertrand et al., 2004) or the American Academy of Pediatrics (AAP) FASD Algorithm and Tool Kit (AAP, 2011).

An algorithm for the evaluation of FAS/FASDs in the medical home can be found within the freely downloadable AAP FASD Toolkit. See http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/Algorithm-for-Evaluation.aspx. While primary care clinicians can diagnose FAS based on the *Fetal Alcohol Syndrome:Guidelines for Referral and Diagnosis* (Bertrand et al., 2004), this new algorithm for evaluation of FASDs within the medical home can further help pediatricians navigate the steps towards the identification, diagnosis, and management of these conditions. This provides a visual, stepwise approach for a clinician who is faced with a child or adolescent who has characteristics of or is at high risk for an FASD. Within this algorithm, the pediatric clinician is guided to make the diagnosis of FAS based on specific central nervous system abnormalities, growth deficits, and presence of specific facial features. In the presence of some but not all of the criteria required for a diagnosis of FAS, the algorithm encourages the provider to make a referral to a specialist. This referral might be to an FASD clinic in their area, a qualified developmental-behavioral pediatrician, or a neurologist or geneticist to rule out other developmental, neurologic or genetic disorders that are similar to FAS. Referral to medical specialists, psychologists, school evaluators, and developmental specialists to further elucidate developmental, psychological, educational, and medical needs is also a very important role for primary care clinicians.

While the facial characteristics are often what point pediatric clinicians to the diagnosis of FAS, poor growth (prenatal, postnatal, or both) is an area that the pediatrician might pay particular attention to since obtaining this information is standard for the pediatric visit. For the child with characteristic facial features and growth problems, possible FAS should be considered in addition to pursuing nutritional treatments. A facial photographic screening tool has been developed that may be useful in the identification of possible FAS or an FASD (Astley, Stachowiak, Clarren, & Clausen, 2002).

After referring children with FASDs to specialists, pediatricians should follow up with families about the recommendations of those specialists. Specialists might not be well-educated on the neurodevelopmental issues with which clients struggle. A child with an FASD might not fully understand the recommendations of the specialist, nor be able to organize all of the information to follow up on treatments.

Pediatricians need to be equipped with the skills to speak to a mother about her possible alcohol and other drug use when evaluating a child who might have been exposed to alcohol in utero. In addition, a pediatrician might need to refer the mother for assessment or possible addiction treatment services to prevent future birth exposures. It is best to think about how to handle such a

situation before it arises and be prepared with information and potential referrals (Chang et al., 2005).

FASD clinic/diagnostician
For individuals who have signs or symptoms but do not meet full criteria for FAS, referrals to an FASD diagnostic clinic, developmental-behavioral pediatrician, geneticist, and/or neurologist can assist in the diagnostic and evaluation process. Typically, FASD clinics have a combination of the following: developmental-behavioral pediatrician, psychologist or neuropsychologist, speech-language pathologist, occupational therapist, and/or social worker. Evaluations in an FASD clinic help elucidate the child's or adolescent's particular strengths and challenges and generally include a combination of IQ and educational achievement testing, neuropsychological testing, speech language testing, occupational therapy testing, and social work/care coordination (Zevenbergen & Ferraro, 2001).

Other medical issues. Individuals with FASDs may require referral or consultation with a variety of other specialists as well.

- Eye/vision and ear/hearing involvement: Research has shown that prenatal alcohol exposure affects fetal midface development (Astley & Clarren, 2001; Schneider, Moore, Kraemer, Roberts, & DeJesus, 2002) resulting in several eye anomalies, most notably small palpebral fissures noted in the diagnostic criteria. Other eye anomalies include ptosis (drooping eyelid), strabismus (deviation of the eye), myopia (nearsightedness), hypoplasia (underdevelopment of the optic nerve), and tortuosity or twisting of the retinal vessels (Jones, 2006). Hearing and vision problems also have been associated with prenatal alcohol exposure (Nash, Sheard, Rovet, & Koren, 2008; Manning & Hoyme, 2007); thus, referral to an otolaryngologist or an ophthalmologist might be appropriate.

- Palatal concerns: Plastic surgeons are often contacted when a child with an FASD has a cleft lip or palate, a rare birth defect associated with very heavy alcohol exposure (Damiano et al., 2007). The lip and palate begin forming during the early weeks of gestation, when a woman often does not know she is pregnant. A notch or cleft is created when the tissues of the developing mouth or oropharynx do not fuse together properly.

- Growth concerns: An endocrinologist, gastroenterologist, or nutritionist might be involved to assess for medical problems that can affect growth or lead to failure to thrive (e.g., thyroid problems, celiac disease, mental health problems) and be part of the differential diagnosis process as well as ongoing monitoring.

- Immune system concerns: Children with FASDs, especially young children, seem to have poorly functioning immune systems that make them vulnerable to colds, flu, and especially frequent bouts of otitis media (Yuan, Sorensen, Basso, & Olsen, 2004). Referral to or consultation with an otolaryngologist, audiologist, or immunologist might be warranted.

▪ Spinal concerns: Depending on clinical findings (e.g., abnormal reflexes), children should be evaluated for potential spinal anomalies. Persistent urinary and bowel incontinence should prompt evaluation for a tethered cord.

▪ Cardiac/renal abnormalities: Some children with FASDs may have cardiac or renal abnormalities that should prompt further investigation.

▪ Sleep problems: Sleep problems are common in children with FASDs and are often categorized under problems with self-regulation. In fact, this may be one of the initial reasons for a medical consult. Sometimes, improving sleep habits improves the child's overall functioning during the day. Given the neurobehavioral roots of this disorder, however, many children with FASDs require a sleep study and/or psychopharmacological interventions. Not much literature exists specifically on the topic of sleep issues in individuals with FASDs. In one study of children 5-8 years of age with FASDs, mean sleep duration was 7.4 hours and mean sleep onset delay was 59 minutes (Stade et al., 2008). In addition, 82% reported other sleep disturbances such as night terrors or waking up twice during the night (Stade et al., 2008). Sensory processing deficits are common in children with FASDs and have been associated with multiple sleep problems (Wengel, Hanlon-Dearman, & Fjeldsted, 2011). However, a recent review by Jan and colleagues confirms that while the epidemiology of sleep disturbances is not clearly understood, addressing and improving sleep habits in these individuals can improve other aspects of this behavioral disorder. The authors further suggest that caretakers and families of children affected by sleep issues need to work to incorporate sleep promotion activities into their routines and establish routines with proper sleep hygiene (Jan et al., 2010).

Pharmaceutical considerations. At present, no medications have been approved specifically for the treatment of FASDs. However, several classes of medications are prescribed routinely to address common symptoms, negative behaviors, or other concerns for individuals with FASDs. Because children often see many professionals before receiving a diagnosis of a condition along the continuum of FASDs, they might present with multiple medications prescribed by multiple providers (with or without communication between providers). As a first step, it is important to evaluate the appropriateness, impact, and potential interactions of these medications. Second, monitoring of medications is essential for these individuals since they might encounter multiple caregivers, chaotic living situations, developmentally challenging behaviors, and negative side effects. Below is an overview of the major classes of medications used for children with FASDs. This list should not be considered exhaustive. Before prescribing any medications for individuals with FASDs, current research and dosage information should be consulted.

Stimulant medications
Attention problems are the most common behavior disorder treated with medication in children (Doig, McLennan, & Gibbard, 2008). Children with FASDs often have attention problems such as shifting their attention or encoding material (Mattson et al., 2010). These problems are in

contrast to those of children with attention-deficit/hyperactivity disorder (ADHD) not resulting from prenatal alcohol exposure, who have difficulty with focus and maintaining attention (Mattson et al., 2010). Thus, stimulant medications might or might not be effective for any particular individual with an FASD. The primary stimulant medications include methylphenidate (Ritalin), dextroamphetamine sulfate (Dexedrine, etc.), dextroamphetamine saccharate or amphetamine sulfate (Adderall), and pemoline (Cyclert). These medications stimulate the central nervous system in areas that control impulses, attention, and self-regulation. With these medications, improvements might be expected in symptoms such as overactivity, inattention, impulsivity, and noncompliance, as well as other secondary behavior issues (Doig et al., 2008).

Antidepressants
Depressive symptoms in children, including children with developmental disabilities such as FASDs, have been reported to be similar to those of adults with sad mood or affect, loss of interest, and sleep problems. In addition, for children, depression often includes school disruption, negativity, irritability, aggression, and anti-social behaviors (Calles, 2008). Thus, antidepressants might be prescribed for individuals with FASDs. Older antidepressants, such as monoamine oxidase inhibitors (MAOI) or lithium, tend to not be prescribed to children. New compounds, selective serotonin reuptake inhibitors (SSRI), are readily prescribed to children with FASDs (Lockhart, 2003). The most familiar SSRIs are fluoxetine (Prozac), sertaline (Zoloft), paroxetine (Paxil), and fluvoxamine (Luvox). Other antidepressants that might be prescribed alone or in combination with SSRIs include alpha-2 adrenergic agonists, such as clonidine (Catapres) and bupropion (Wellbutrin) (Feldman, Meyer, & Quenzer, 1997). Because mood disorders, especially in children, are often secondary to other organic or developmental issues, the effectiveness of using antidepressants is unclear. However, some reduction in behavior problems, particularly aggression, might be expected (Calles, 2008).

Neuroleptics
Psychotic symptoms are not associated with FASDs. However, neuroleptics are prescribed to children with developmental disabilities, including FASDs, to address aggression, anxiety, or behavior regulation. Neuroleptics prescribed might include risperidone (Risperdal), clozapine (Clozarile), and thiroridazine (Mellaril). Neuroleptics might be used in combination with antidepressants or anti-anxiety medications. There are numerous major and minor side effects associated with neuroleptics (Calles, 2008). Before prescribing these medications, providers should be sure parents understand these side effects so they can weigh the advantages and disadvantages for their child.

Anti-anxiety drugs
Anxiety disorders among children are more common than previously thought, with many psychiatric conditions actually having their basis in anxiety (e.g., conduct disorder) (Szymanski & King, 1999). The number of children prescribed anti-anxiety medications can be expected to rise. The most common medications that are generally recommended for pediatric anxiety are still the SSRIs such as sertraline (Zoloft), alprazolam (Xanax), clonazepam (Klonopin), and lorazepam (Ativan). Benzodiazepines (Diazepam/Valium) are more commonly used for adults.

Drug polypharmacy
As mentioned, many children, adolescents, and adults with developmental disabilities, including those with FASDs, are prescribed multiple medications. Such multiple prescriptions can result from patient failure to disclose current medications, a lack of communication across providers, or a failure to discontinue medications that are ineffective or no longer appropriate. Patients, parents, and the education and medical communities are becoming increasingly concerned about multiple medications and their possible negative effects. Further, because research into drug therapies tends not to include multiple drugs, their interactional effects have not been studied. As new medications are considered, they should be reviewed fully to assess the need and effectiveness in the context of all current medications (Feldman et al., 1997).

Emerging therapies.

Choline supplementation
There are no known biological treatments for neurobehavioral, neurodevelopmental, and neurobiological deficits in FASDs. There has been some work with animal models in which choline supplementation appears to attenuate some of the adverse effects of prenatal alcohol exposure on the brain, and improve cognitive and behavioral outcomes in the offspring (Thomas, La Fiette, Quinn, & Riley, 2000; Thomas, Garrison, & O'Neill, 2004). To date, however, a safe amount of choline has not been determined in humans and therefore, choline supplementation is not a recommended treatment for those with FASDs.

Dietary intakes
Until recently, the issue of dietary intake in children with FASDs was an understudied area of research. Two recent studies addressing this issue have now been completed: one in children 2-5 years of age (Fuglestad et al., 2013); and one in children with a mean age of 9.6 years (Werts, Van Calcar, Wargowski, & Smith, 2014). These studies have shown that children with FASDs have feeding problems or inappropriate feeding behaviors, including constant snacking, lack of satiety, picky eating, and poor appetites. Additionally, although caloric intakes and macronutrient intake were not significantly different from those of children in the control group, children with FASDs did not meet the recommended intakes for several nutrients, including fiber, n-3 fatty acids, essential fatty acids, vitamins A, D, E, and K, calcium, iron, and choline (Fuglestad et al., 2013; Werts et al., 2014). These findings are consistent with data from pre-clinical studies, and suggest that children with FASDs may be at risk for nutrient deficiencies, and that nutritional interventions might have important potential for attenuating neurodevelopmental deficits.

Animal-assisted therapy (AAT)
One commonly documented strength among individuals with FASDs is that they tend to work well with animals. AAT is delivered by a professional service provider, such as a recreation therapist, and is designed to promote improvements in physical, emotional, social, or cognitive functioning. Animals used in AAT can include cats, rabbits, birds, fish, and perhaps most commonly, horses and dogs.

Genetics/epigenetics

Recently, investigation of possible epigenetic mechanisms as potential mediators of alcohol's adverse effects on the fetus has provided another promising approach for understanding the diverse phenotype associated with FASDs (Kobor & Weinberg, 2011; Kleiber et al., 2014; Warren, Hewitt, & Thomas, 2011). The phenotype of the child depends on an interaction between genes and environment (including alcohol), and epigenetic mechanisms may function as mediators linking the genome to environmental signals and exposures (Kobor & Weinberg, 2011). The term epigenetics refers to stable but potentially reversible changes in the genetic information within the cell that change gene expression (whether and how much genes are turned on or off) but do not involve changes in the underlying DNA sequence (mutations). Because epigenetic changes can persist long after an environmental signal or exposure has disappeared, and can even be passed on to the offspring in the next generation, epigenetic mechanisms are particularly important and relevant for FASDs.

The timing and level of alcohol exposure clearly affect the type and severity of the adverse effects that are observed in children with FASDs. However, the specific type and extent of deficits that are observed in children exposed to alcohol in utero can vary significantly, even among individuals with similar levels of exposure. Multiple direct and indirect mechanisms, activated at different stages of development and/or at different dose thresholds of exposure, likely contribute to these varying deficits (Goodlett, Horn, & Zhou, 2005). Recent studies have examined genes that are thought to be the target of alcohol's teratogenic effects and thus may underlie, at least partly, susceptibility to FASDs. Several genes involved in various cell-signaling pathways, which are important in development of the embryo and fetus, are now being studied. In addition, several studies have begun to identify candidate genes, by cross matching animal model gene expression data with human genetic linkage data and data from human tissues (Chudley, 2011).

Future studies focused on genetic and epigenetic mechanisms, on potential links between the two, and on links between these mechanisms and neurobiological/physiological/behavioral outcomes are essential for elucidating critical mechanisms through which alcohol can interact with key target pathways to reprogram gene expression and thus alter development and function of offspring exposed to alcohol in utero.

B. Behavioral and educational interventions

Until recently, information and strategies for behavioral and educational interventions specific to individuals with FASDs have been gleaned from interventions for populations with other disabilities and from the practical wisdom of parents and clinicians gained through trial and error and shared through informal networks. Although informative to a limited degree, such treatments have been implemented without being evaluated systematically or scientifically. In general, helpful interventions should include ensuring stable home environments and working with educational staff or therapists and social services (e.g., foster care) to determine individualized treatment plans.

When a developmental delay or risk of developmental problems is suspected in a child under three years of age, that child should be referred to early intervention programs, which encompass specialties such as physical therapy, occupational therapy, speech pathology, and special education. Early intervention programs are available in all states under the Individuals with Disabilities Education Act (IDEA), which was reauthorized under the Individuals with Disabilities Education Improvement Act of 2004 (U.S. Department of Education, 2004). An increasing number of effective strategies can be used in the classroom setting to teach children with FASDs. These can include using "hands on" activities and concrete examples, breaking down tasks and reducing lesson size, individualizing instruction to address ability and not grade level, giving instructions at their own pace, and helping them recognize their unique strengths and challenges (Edmonds & Crichton, 2008; Carpenter, 2011).

It is essential that practitioners understand the core cognitive issues of children with FASDs. Their learning style might not "fit" into many programs designed to address some of the presenting difficulties. For instance, most risk-reduction programs designed to address sexual assault or drug use are based on learning theory models for students who do not have learning disabilities. A student with an FASD who is a concrete thinker might not benefit from a model that is based on intellect and common sense approaches to safety. Programs must be adapted to consider brain differences of students with FASDs.

Some physicians and other health care professionals might be asked to include documentation to support a child's individualized education program (IEP). An IEP is a written statement outlining goals and objectives for the child's progress in school. Parents, teachers, and counselors collaborate to create a unique plan to meet the needs of the child based on a formal evaluation. The purpose of an IEP is to provide an appropriate educational program for a child who has specific learning disabilities or has difficulty functioning in a regular classroom setting. If a child has an FASD, that child has a right to an IEP (U.S. Department of Education, 2006).

In addition to educational services, several adaptive interventions have been shown to be effective for children with FASDs (Bertrand, 2009). *Project Bruin Buddies* assessed a social skills training program to improve peer friendships for children with FASDs. Researchers found that after controlling for covariates, children with FASDs in a 12-week children friendship training group showed statistically significant improvement in their knowledge of appropriate social behavior compared to controls (Schonfeld, Paley, Frankel, & O'Connor, 2009). The Georgia *Math Interactive Learning Experience* (MILE) program demonstrated effectiveness of adaptive materials and tutoring methods to improve math knowledge and skills in children with FASDs, compared to controls with FASDs (Kable et al., 2007). Using the *ALERT* program (Wells, Chasnoff, Schmidt, Telford, & Schwartz, 2012), researchers in Chicago have demonstrated improvement in behavior regulation and executive function in children with FASDs, compared controls. In Seattle, researchers have used an intensive 9-month individualized parent therapy program to improve parent effectiveness and reduce clinically significant behavior problems in school-age children with FASDs (Olson, Oti, Gelo, & Beck, 2009). All of these programs were later tested in community settings and found to be effective.

Little is known about effective interventions for youth and young adults with FASDs; however, two recent randomized controlled trials offer interesting insights. One study addressed alcohol misuse and the other provided a multi-component intervention to address maladaptive behaviors. *Project Step Up* (O'Connor, Dipple, & Quattlebaum, 2014) revealed fewer numbers of drinks over the last month, less high risk drinking, and fewer alcohol-related negative consequences at post treatment for adolescents in the treatment group compared to controls. *Partners for Success* provided a three-fold intervention including home-based therapy for the family, mentoring for the young adult, and a caregiver support group indicating efficacy for improvement of coping style and overall understanding of the condition (Tenkku et al., 2014).

These research studies are important because they advance scientifically validated, efficacious interventions that can address the needs of children, youth, and young adults with FASDs. Controlled studies suggest that targeted interventions do improve outcomes and that affected individuals respond to standard treatments that are adapted to their individual special needs. Finally, these studies provide evidence that early identification and intervention are of primary importance in the prevention of secondary disabilities in behavioral, emotional, and educational areas for individuals with FASDs.

C. Mental health

Two other specialties often involved in the identification and care of individuals with FASDs are neurologists and psychiatrists. Undisputed is the fact that prenatal exposure to alcohol can cause lifelong brain damage resulting in structural, neurological, and functional deficits (Sowell et al., 2008). As such, neurologists are often involved in the exclusionary process of diagnosis. Individuals with FASDs frequently have work-ups for ADHD or evaluation of motor coordination problems before proper diagnosis with an FASD. After diagnosis, monitoring and treatment for these issues by a neurologist might be appropriate.

Psychiatrists also play an important role in identifying individuals before diagnosis and providing treatment throughout the life span. The attention, attachment, abuse/neglect, and behavioral problems associated with FASDs are often evaluated by mental health professionals, especially child psychiatrists and psychologists, school psychologists, and behavior management specialists. Examining the possibility that the behaviors for which an individual is evaluated are a result of an FASD is an important part of the differential diagnosis process. If these problems are identified as being related to prenatal alcohol exposure, therapy, family treatment, and medication management by a psychiatrist might be effective (Lockhart, 2003). Due to the increasing awareness and incorporation of treating individuals with FASDs with an interdisciplinary approach, mental health providers are a necessary component of treating an individual with an FASD throughout the life span.

Trauma. One of many complicating factors in the treatment of individuals with FASDs is trauma. The effects of adverse childhood events (ACEs), including trauma, overlap with many effects of prenatal alcohol exposure including developmental delays (Henry, Sloane & Black-Pond, 2007), mental health concerns including mood and anxiety disorders (Anda et al., 2006; Chapman et al., 2004), sleep disturbances (Chapman et al., 2011) and increased substance use

(Mersky, Topitzes, & Reynolds, 2013). For a complete review of the Adverse Childhood Events (ACEs) study, please see: http://www.cdc.gov/violenceprevention/acestudy/about.html and www.acestudy.org.

The effects of prenatal alcohol exposure and trauma on childhood development, health, and behavior are typically studied separately; however, exposure to both has substantial potential to dramatically alter normal development. In fact, the combination of both FASDs and trauma has been shown to have a significantly greater impact on neurodevelopment than trauma alone (Henry et al., 2007). Children exposed to prenatal alcohol exposure in addition to postnatal trauma tend to have lower IQs; greater deficits in language, memory, motor skills, visual processing, and attention; and increases in oppositional behavior, poor attention, hyperactivity, impulsivity, and social problems (Henry et al., 2007).

Given the estimated prevalence of FASDs and the fact that traumatic events affect millions of children every year, increased awareness of this combination must be considered when developing any treatment plan for individuals affected by FASDs. Without knowledge of both impacts to health and behavior, interventions may be missing key components for effectiveness. More research in this emerging field is necessary.

D. Primary and secondary disabilities

A myriad of conditions can also affect individuals with FASDs (see Figure 6.2). The most common secondary disability associated with FASDs reported in the literature has been ADHD (O'Malley & Storoz, 2003; Peadon & Elliott, 2010). The prevalence of individuals with FASDs diagnosed as having ADHD has been reported as high as 94%, with higher rates in younger children compared to older children (Bhatara, Loudenberg, & Ellis, 2006; Fryer et al., 2007). Given this overlap, the relationship between FASDs and ADHD is still unclear. As stated previously, children with FASDs are frequently evaluated for ADHD and are often misdiagnosed before a proper diagnosis with a condition along the continuum of FASDs is derived.

The life experience of the individual may impact and exacerbate the presence of mental health conditions such as post-traumatic stress disorder (PTSD), anxiety disorder, and depression. Children with FASDs may have faced traumatic childhood events including abuse and neglect, experienced poor attachment with caregivers, and been placed in multiple home environments as part of the foster care system. All of these challenges can increase the incidence of mental health problems in early childhood and adolescence.

Figure 6.2.   Secondary Disabilities of FASDs
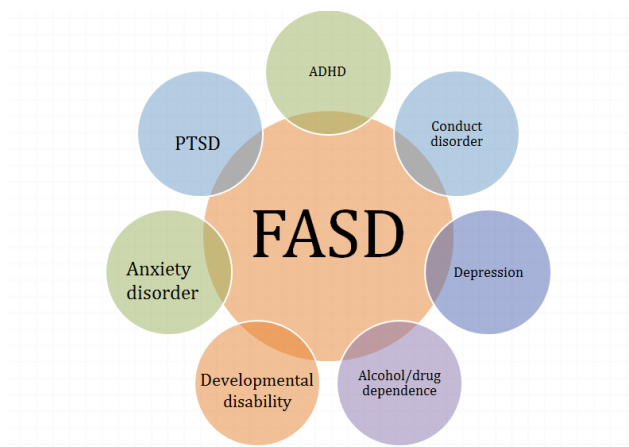
Source: Doll, J. D. (2013). The role of occupational therapy with fetal alcohol spectrum disorder (FASD). Retrieved from http://www.heartlandcenters.slu.edu/mrfastc/ot/

III. Support services and resources

A. Disability services

There are several federally-funded programs that may be appropriate to increase services and support to individuals with FASDs, families, and the professionals who serve them. FAS is a recognized diagnosis for disability determination under the Social Security Act Program. Documentation can be found in Section D2 under 10.00 Congenital Disorders that Affect Multiple Body Systems (http://www.ssa.gov/disability/professionals/bluebook). Completing and submitting this document is a good first step following a diagnosis of a condition along the continuum of FASDs regardless of the age diagnosis is confirmed. There is no guarantee, however, that an application will get approved. Many factors are taken into account including functional level, family resources, and previous work history for adults.

The National Organization on Fetal Alcohol Syndrome (NOFAS) maintains a national resource directory where health care providers and family members can find specialists by state who might be familiar with FASDs, such as a developmental pediatrician. http://www.nofas.org/resource-directory/

For younger children, the following services may be helpful:

Early intervention services are designed to help infants and toddlers with physical, cognitive, and social disabilities. Federally funded, these services are available in every state: http://www2.ed.gov/programs/osepeip/index.html

Additionally, a list of early intervention contacts by state can be found through the *Learn the Signs. Act Early.* program at CDC. http://www.cdc.gov/ncbddd/actearly/parents/states.html

Parent Technical Assistance Centers provide information, support, and referral. http://www.parentcenterhub.org/ptacs/

State Councils on Developmental Disabilities advance public policy and systems change and include training and technical assistance: http://www.acl.gov/programs/aidd/Programs/DDC/index.aspx

Respite services provide caregivers short-term services that provide temporary relief and support: https://www.childwelfare.gov/topics/preventing/programs/respite/

Individualized Education Programs provide individualized plans to address student strengths and challenges in school – U.S. Department of Education: http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CTopicalBrief%2C9%2C

The Center for Parent Information and Resources provides an overview of several national websites and programs that offer additional information on key services. http://www.parentcenterhub.org/

For adolescents and adults, the following additional services can be helpful:

State Vocational Rehabilitation (VR) programs, federally funded through the Rehabilitation Services Administration (RSA), support adults with physical and/or mental disabilities to obtain meaningful employment and increase independence. Transition services from school to work typically start during the high school years, but can be also be accessed anytime during adulthood. Specific providers are listed by state: https://rsa.ed.gov/

The Aging and Disability Resource Centers (ADRC) are federally funded programs that support state efforts to provide long-term support services to older adults and individuals with disabilities, including those with FASDs, if they qualify. Services are listed by state: http://goo.gl/X3YWxp.

B. Parenting strategies

Parents and caregivers of children with FASDs may require longer-term support as their commitment to parenting often extends into adulthood. It is significant to acknowledge that the journey of parenting children with FASDs involves challenges and rewards, and those who are most successful have a good understanding of the lifelong deficits associated with these disorders (Mukherjee, Wray, Commers, Hollins, & Curfs, 2013). Several factors are associated with positive functioning. Families raising a child who has received a diagnosis of FAS may experience significantly lower distress and negative emotion than those raising a child with another condition on the spectrum, or exposure with no diagnosis (Wilton, 2003). Further, increased family hardiness is associated with both decreased family distress and parental

negative emotion. Family hardiness is a particular strength possessed by a family, a "durability" that can buffer stress. Components of hardiness, as measured by the Family Hardiness Index (FHI), include confidence (reflecting a family's ability to plan ahead), control, and commitment (Wilton, 2003).

Providers and families should acknowledge the challenges in parenting children with FASDs. Failed adoptions and foster placements are highly correlated with situations where FASDs are not well understood by the caregivers (Brown, Bednar, & Sigvaldason, 2007). It is also significant to recognize that birth parents may be impacted by social stigma, which may further affect one's ability to parent a child with an FASD (Caley, Winkelman, & Mariano, 2009). Divorce rates, reported stress levels, and the risk for social isolation are high (Mukherjee et al., 2013). Birth parents may also need mental health support to deal with feelings of guilt (Phung, Wallace, Alexander, & Phung, 2011). Despite all these challenges, there are strategies caregivers can apply in parenting a child with an FASD. Providers should note that parents are more successful when served by a team of professionals who understand the diagnosis and provide support to the person with an FASD, the parents/caregivers, and the family.

One of the most researched and supported aspects of success in parenting children with FASDs is attachment. Attachment needs to begin, if possible, at birth. Literature has revealed that poor attachment before the age of six months exacerbates many social-emotional problems for individuals with FASDs (Koponen, Kalland, & Autti-Rämö, 2009). This does not mean that attachment cannot occur after the age of six months, but it may become more difficult to develop. Parents often report challenging behaviors among infants and children with FASDs including being easily irritable, difficult to feed, and poor sleepers (Koponen et al., 2009). These behaviors may make attachment with a young child with an FASD even more difficult to establish as parents struggle with these behaviors. Yet, research indicates that "the quality of the postnatal caregiving environment combined with neurophysiological vulnerability are considered to be the most important prognostic factors for the developmental outcome of children prenatally exposed to alcohol" (Koponen et al., 2009, p. 1050). A stable home environment contributes to decreases in issues with behavior, while an unstable home environment or multiple foster placements contributes to increases in behavioral issues. In one study, a supportive home environment impacted later social and cognitive functioning positively, no matter the level of prenatal alcohol exposure and neurodevelopmental deficits of the child (Koponen et al., 2009).

Ensuring a child's needs are met consistently and lovingly sets a foundation for developing a securely attached relationship between a child and caregiver. Parents may begin by responding to a child's desires to be nurtured by providing love and support through touch and talk. Consistently providing a nurturing environment is crucial to developing trust in a relationship between a child and caregiver. One strategy to facilitate this process is to establish predictable routines for daily activities at a young age, for instance a bedtime and morning time routine. Since neurocognitive deficits are associated with FASDs, children may find every day activities like getting dressed difficult to accomplish unaided. These daily activities have many steps and children may need support in learning and continuing them throughout their lives. Routines, consistency, and visual schedules may assist with success in these activities. As with any child,

parents must understand the child's cognitive abilities, provide tasks that are developmentally appropriate, offer specific instructions, and lots of repetition.

Parents may also acknowledge their child's positive behaviors, providing consistent positive attention, identification, and reinforcement when desired behaviors occur. Often called *positive parenting*, the focus is on accomplishments and successes, not just on challenges. Others may refer to this concept as *strengths-based parenting*, where caregivers focus on the abilities of the child instead of their deficits (Phung et al., 2011). Parents should also recognize that traditional disciplinary approaches may not work for a child with an FASD; it is important to be concrete in discipline to fit with the child's cognitive level.

Parents often have to become the child's advocate, requiring them to learn about social services and education. They frequently also find themselves in the role of educating the school staff (Carpenter, 2011). If possible, parents should explore developing IEPs early on for children to be supported in learning and development. Parents know their child best and can help identify which services are most appropriate. Starting early can ensure a child's success later in life despite neurocognitive deficits. Children with FASDs also perform better in the school environment if their teachers are aware of FASDs and know what to expect.

Many children with FASDs may also be impacted by sensory processing deficits, sometimes called a sensory processing disorder. They may exhibit a wide range of issues due to their brain damage from prenatal alcohol exposure, and their sensory processing challenges may be mistaken for behavioral issues. These issues often disrupt daily activities and may impact both sleep and eating (Wengel et al., 2011). These challenges are often best addressed by an occupational therapy practitioner, who can work with parents to develop a sensory diet and modify the child's environment to help address sensory issues.

Two other approaches important for parents to be aware of are the impact of social stories and neurocognitive habilitation training (also known as social skills training). Children with FASDs tend to struggle in social situations, often play with younger peers, and face vulnerabilities when it comes to bullying and sexual exploitation (Kully-Martens et al, 2012). Parents should begin training for social skills early. One way is to engage children in social stories. Originally developed for children with autism to help them identify how to interact with the world socially (Ozdemir, 2008), social stories provide a step-by-step experience of what to expect in daily situations (e.g., what will happen in a particular order and what feelings might come about due to the experience). Social stories have been shown to be effective as an intervention for children with FASDs (Rasmussen, 2005). Parents can develop social stories with photos of the child or use existing stories from popular characters. Social skills training is another beneficial intervention for addressing challenges in social situations and can also be implemented in both group settings and family-based. Successful social skills programs for children with FASDs include the ALERT Program (Wells et al., 2012) and Project Bruin Buddies (Schonfeld et al., 2009).

Caregivers will also need support to ensure a healthy and supportive environment for the child. Caregivers of young children with FASDs report high levels of stress (Olson et al., 2009). These

stress levels are found across all types of caregivers of children with FASDs including birth parents, family caregivers, adoptive parents, and foster parents (Jirikowic, Olson, & Astley, 2012). Families may disengage due to behavior issues and become socially isolated (Brown & Bednar, 2004). Parents need support and may need to acknowledge that it is okay to get frustrated. Using the concept of "time out" as a parent can help a parent avoid responding inappropriately to a child in a stressful moment (Rutman & Van Bibbner, 2010). Education about the diagnosis and what to expect is critical at this age to ensure stable family relationships and reduce stress.

To deal with the stress of parenting a child with an FASD, social supports and a supportive group of professionals is critical to both the child and the parent. Parents may consider reaching out for respite services. Taking a break is important to help alleviate stress and ensure effective parenting. Unfortunately, many parents may be hesitant to leave the child unless the caregiver has a good understanding of the child. Parent support groups can help parents find resources and possibly start a parent babysitting exchange or co-op where parents of children with FASDs can support other parents for an occasional break. Ways that families can find education and support include:

- FASD community support group
- FASD social media sites
- Professional counseling
- Al Anon Family Groups: Strength and Hope for Families and Families of Problem Drinkers (http://www.al-anon.alateen.org/local-meetings)
- NOFAS Circle of Hope for birth mothers (http://www.nofas.org/circleofhope/)
- FASD workshops and webinars
- Disability support groups

Each child-parent relationship will be unique and will have unique demands. Each child with an FASD will exhibit unique sensory issues and thus, intervention is best addressed based on his or her specific needs (Jirikowic, Olson, & Kartin, 2008).

C. Resources

Resources for families

National Organization on Fetal Alcohol Syndrome (NOFAS):
NOFAS strives to prevent alcohol use during pregnancy through primary prevention, advocacy, and support. NOFAS has information and resources for educators, families, and pregnant women.
http://www.nofas.org/
- NOFAS National Resource Directory: http://www.nofas.org/resource-directory/
- Tools for Parents and Caregivers: http://www.nofas.org/parents/
  o Includes brochure on four intervention programs for children living with FASDs
- Living with FASDs: http://www.nofas.org/living-with-fasd/
- Adults Living with FASDs: http://www.nofas.org/adults-living-with-fasd/

- Circle of Hope – Mentoring Network for Birth Mothers:
  http://www.nofas.org/circleofhope/

University of Washington School of Medicine Fetal Alcohol and Drug Unit (FADU):
FADU is a research unit dedicated to the prevention, intervention, and treatment of FASDs. This site has links to research projects and findings, a list of support groups worldwide, and a list of upcoming international FASD conferences, as well as other resources.
http://depts.washington.edu/fadu/

FAS Community Resource Center:
The FAS Community Resource Center is a Web-based program that provides information and resources and training for parents and professionals.
http://www.come-over.to/FASCRC/

Fetal Alcohol Support, Training, Advocacy, and Resources (FASSTAR):
FASSTAR provides training on all aspects of FASDs, including community awareness, prevention, and intervention. FASSTAR has a unique workshop designed for teens and adults with FASDs and their mentors/caregivers to help maximize success in life.
http://www.fasstar.com/

Fetal Alcohol Disorders Society: Research, Information, Support and Communications (FASlink): FASlink is a Canadian-based organized that provides extensive resources on FASDs and online support for individuals with FASDs and their families.
http://www.faslink.org

Families Affected By Fetal Alcohol Spectrum Disorder (FAFASD):
FAFASD seeks to spread information, awareness, and hope for caregivers of people with FASDs.
http://www.fafasd.org

Family Empowerment Network (FEN):
FEN is a national resource, referral, support, and research program serving families affected by FASDs and the providers who work with them. FEN's mission is to empower families through education and support. Members of FEN include birth and adoptive parents, foster care providers, grandparents, siblings, individuals with FASDs, extended family members, and the providers who work with these families. There is no fee to join FEN.
http://pregnancyandalcohol.org/

Olderfas Support Group:
Olderfas is a support group and discussion list for parents only. They welcome family members caring for older teens with FASDs who are transitioning to adulthood and parents of adults with FASDs.
https://groups.yahoo.com/neo/groups/Olderfas/info

Resources for providers

Fetal Alcohol Syndrome (FAS) Guidelines for Referral and Diagnosis:
This report provides diagnostic guidelines for FAS and information about referrals, services for people with FASDs and their families, and strategies for screening and advising women about risky drinking.
http://www.cdc.gov/ncbddd/fasd/documents/fas_guidelines_accessible.pdf

American Academy of Pediatrics (AAP) FASD Toolkit:
The AAP FASD Toolkit helps to raise awareness, promote surveillance and screening, and ensure that all children living with FASDs receive appropriate and timely interventions. This comprehensive toolkit serves as the framework for the management of a child with an FASD in the medical home. The toolkit includes a variety of resources and tools, such as information on identification, diagnosis, and referral including a clinical decision algorithm and provider checklist; patient management resources such as sample care plans, case studies, scripts for talking with families of children diagnosed with FASDs; practice management tools like how to build an effective FASD team and billing and coding information; frequently asked questions for providers and families; and resources for in-depth training.
http://www.aap.org/FASD

Diagnostic and Statistical Manual (DSM-5):
This new edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is used by clinicians and researchers to diagnose and classify mental disorders. See also Competency V.
http://www.appi.org/products/dsm-manual-of-mental-disorders

National Organization on Fetal Alcohol Syndrome (NOFAS):
NOFAS's Website hosts a comprehensive list of resources for prevention, diagnosis, and management of FASDs, including specific pages that are helpful to health care providers.
http://www.nofas.org
- Recognizing FASDs: http://www.nofas.org/recognizing-fasd/
- Treatment & Support: http://www.nofas.org/treatments-support/
- Living with FASDs: http://www.nofas.org/living-with-fasd/
- Fact sheets for specific audiences, including health care providers: http://www.nofas.org/factsheets/

Federal Resources

National Institute on Alcohol Abuse and Alcoholism (NIAAA):
NIAAA is one of the 27 institutes and centers that comprise the National Institutes of Health (NIH). The NIAAA supports and conducts research on the impact of alcohol use on human health and well-being. It is the largest funder of alcohol research in the world.
http://www.niaaa.nih.gov

SAMHSA FASD Center for Excellence:
The SAMHSA FASD Center is a federal initiative devoted to preventing and treating FASDs. This Web site provides information and resources about FASDs, including materials to raise awareness about FASDs. Additionally, the center is dedicated to providing training, technical assistance, and conference and event speakers.
http://fasdcenter.samhsa.gov/

Centers for Disease Control and Prevention (CDC):
The mission of CDC's National Center on Birth Defects and Developmental Disabilities is to promote the health of babies, children, and adults and enhance the potential for full, productive living by working to identify the causes of birth defects and developmental disabilities; help children to develop and reach their full potential; and promote the health and well-being among people of all ages with disabilities, including blood disorders. The center's Fetal Alcohol Syndrome Prevention Team works to prevent FASDs and to ameliorate these conditions for individuals and families already living with FASDs.
http://www.cdc.gov/fasd
   - Information for Families: http://www.cdc.gov/ncbddd/fasd/families.html
   - Information for Health Care Providers: http://www.cdc.gov/ncbddd/fasd/hcp.html
   - Information for Educators: http://www.cdc.gov/ncbddd/fasd/educators.html

Suggested Learning Activities

   - Have an experienced case manager or social worker describe case management issues.
   - Have a group discussion on the barriers, challenges, and opportunities that arise for individuals with FASDs across the lifespan.
   - Use case studies to problem solve on case management issues.

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Competency VII: Ethical, Legal, and Policy Issues

Carolyn Szetela, PhD; Kathleen Mitchell, MHS, LCDAC; Tom Donaldson; Robert Levine, MD; and Danny Wedding, PhD, MPH

The health care student or provider will be able to recognize ethical, legal, and policy issues related to FASDS and alcohol use during pregnancy.

Learning Goals

VII-A Identify ethical issues related to FASDs.

VII-B Identify legal and policy issues for individuals and families affected by FASDs.

VII-C Identify legal and policy issues in the maternal-fetal relationship.

Content Outline for Competency VII

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II. Legal and policy issues for individuals and families living with FASDs
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IV. Summary

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I. Ethical issues

A. Principles of ethics for health care

All health care delivery involves ethical dimensions. Health care related to fetal alcohol spectrum disorders (FASDs) is laden with ethical issues such as:

- Weighing the rights of a pregnant woman,
- Protecting the health of the fetus, and
- Providing optimal care for individuals with FASDs.

Health care practitioners are key players in advocating and delivering the best care to address these issues. Those who thoughtfully consider the ethical aspects of their work are equipped to make better decisions for their patients and communities as well as uphold their personal integrity.

Four major principles are commonly used to describe ethical dimensions of providing health care (Beauchamp & Childress, 1983). These are autonomy, beneficence, nonmaleficence, and justice. In practice, these principles often conflict with one another, and no principle can be regarded as absolute. Health care providers, along with their patients and other appropriate decision makers, must determine which principles to give priority in response to each unique situation.

> **Autonomy**: Health providers should permit patients with adequate decisional capacity to make their own health decisions.

Respect for autonomy asks health care providers to consider a patient's right to self-determination in making health decisions. A well-known expression of the importance of autonomy in American medicine is the 1914 statement by Supreme Court Justice Benjamin Cordozo that "every human being of adult years and sound mind has a right to determine what shall be done with his body" (*Schloendorff v. Society of New York Hospital*, 1914). To have the capacity for autonomous choice a person must have the ability to *reason*, as well as the ability to make a *voluntary choice*. Adults normally have the capacity for autonomy. However, fetuses, children, and adults with cognitive limitations, such as those that can occur with FASDs, are lacking or limited in the reasoning skills needed to exercise full autonomy. Persons with alcohol dependence or addiction might also have limited autonomy because of impaired reasoning and/or compulsion.

Pregnant women and adults caring for someone with an FASD are typically free to make autonomous health care decisions for themselves, their fetus, or child. The mother, parent, or guardian is expected to be an advocate for the fetus' or child's interests. At times a health care provider might question the reasonableness of a patient's choice for her own care or for her fetus or child. In these cases, the provider might seek to influence the health decision through expanded education and informed consent processes. If such educational efforts are

unsuccessful, the health provider might consider available and legally permissible ways to limit the adult's authority to make the decision of concern.

> **Beneficence:** Health providers should promote their patients' best interests and well-being.
>
> **Nonmaleficence**: Health providers should refrain from exposing patients to intentional or unwarranted harms.

Beneficence asks health care providers to act in ways that benefit their patients. This is an integral goal of health care, described as a "helping profession." Beneficence applies when health care providers act to promote maternal and fetal health and provide competent, compassionate care for persons living with FASDs. Nonmaleficence, also known as the principle of "do no harm," focuses on the obligation to avoid acts of intentional harm and acts that expose patients to undue risks of harm. In contrast to acts of beneficence, nonmaleficence applies when health providers *avoid* acts. Examples include refraining from incompetent care and avoiding treatment options that would expose women, fetuses, and persons with FASDs to undue harm.

The principles of beneficence and nonmaleficence routinely work together as health providers weigh the benefits and risks of all reasonable options in caring for patients. Health providers should recommend medical interventions only when their potential benefits are judged to exceed the harms. For example, a patient with an FASD may present with problems related to attention deficit hyperactivity disorder. The health provider may consider a standard ADHD medication among the options for treatment. The provider will consider the likelihood of the patient to experience a beneficial response to the medication, as well as the potential for harmful side-effects and consequences. If the provider expects the potential benefits of the medication to outweigh its potential harms to a greater degree than alternatives, beneficence guides the provider to offer the medication. If the provider expects the potential harms to outweigh the potential benefits, nonmaleficence guides the provider to avoid the medication and continue to seek the most favorable alternative. Whenever health providers seek to maximize benefits and avoid harm to their patients, they are activating the principles of beneficence and nonmaleficence.

> **Justice:** Health providers should treat all patients fairly.

The principle of justice asks health care providers to seek fair distribution of health care benefits and burdens (distributive justice), and to promote and follow health care laws and practices in ways that are fair for all people (procedural justice). Justice requires fairness to people who are living with FASDs and to women with alcohol use disorders. Justice can be reflected in non-prejudicial attitudes and treatment of persons with FASDs and women with alcohol problems, and in promotion of access to the resources they need. For example, at a recent international meeting, Dubovsky (2013) urged that fair treatment for people living with FASDs and their families include appropriate access to treatment and supports, promotion of safety and security,

respect for their desires for control over their lives, and recognition of their strengths, abilities, and value.

> **Respect for Persons:** Health providers should respect patients' inherent worth and value.

An additional and broad ethical principle, *respect for persons*, adds to the four major principles described above. Respect for persons, as applied in a health context, asks care providers to respect and honor each person's dignity and interests. People are to be treated as "ends in themselves" and not as mere means for achieving the goals of others. In the context of FASDs, this principle asks health care providers to show respect for people with FASDs and women with alcohol use disorders, and to address their health care needs and interests.

These basic principles together provide a framework for health care professionals, patients, and others to consider ethically challenging health care decisions. In instances when the principles conflict, decision makers can take into account how each principle applies in the context of the situation and then weigh which principle(s) should prevail.

Health care providers must also consider relevant city, state, and federal laws as they strive for ethical decision making. In some cases ethical and legal directives might conflict. For example, laws of the 1900's permitting forcible sterilizations for eugenic ("better breeding") purposes in the United States are now seen as violations of the ethical principles of autonomy, beneficence, nonmaleficence, justice, and respect for persons. When existing or proposed health care laws conflict with fundamental ethical values, they should be subject to review and revision (American Medical Association [AMA], Council on Ethical and Judicial Affairs, 2015).

B. Confidentiality

Confidentiality is an essential aspect of the health care provider–patient relationship. Health care providers obtain personal information about their patients for the primary purpose of delivering health care that serves the patient's interests and preferences. Patients expect that the information they disclose will be held in trust, thus protecting their privacy and promoting their comfort in disclosing personal information.

The principle of confidentiality is not absolute. Among its possible exceptions are cases where health care providers learn information that might, with reasonable probability, indicate serious bodily harm to the patient or others (AMA, 2015). This may include reporting confidential information to protect a woman with alcohol problems, a pregnant woman who drinks alcohol, or a child with an FASD. In addition, child abuse statutes require health care providers to share otherwise confidential information with state child protection agencies if they have reasonable suspicion that a child's health or safety is jeopardized.

Care providers have a duty to honor patient confidentiality to the greatest degree possible, consistent with ethical, legal, and policy restrictions. While they seek to protect individual confidences, they should avoid giving a false impression that confidences might always be

protected (AMA, 2015). Accordingly, care providers should inform patients about general limitations on confidentiality in their practice setting at the first health visit with the patient. When confidentiality must be breached, health care providers should notify the individual of their need to disclose, unless impractical or inadvisable (AMA, 2015). Care providers must stay informed of local, state, and federal laws that impact confidentiality, including the Health Insurance Portability and Accountability Act (HIPAA).

Confidentiality and disclosure considerations: FASDs. Confidentiality and disclosure can be sensitive issues when helping individuals with FASDs and their families. Having an FASD can lead to stigma, judgment, and harm towards a person and others in their social circles. Common misunderstandings about FASDs too often result in school employees, employers, service providers, health care providers, and others showing negative biases toward individuals living with FASDs. Health care providers have an ethical obligation to be aware and sensitive to these issues and can help patients and families avoid being harmed by disclosures of potentially stigmatizing information.

One might expect people to respond with support, understanding, and appreciation for individuals or families they learn are living with FASDs. However, people with FASDs, birth mothers, fathers, adoptive parents, and other family members frequently experience negative responses instead. Individuals and families may feel uncertain about whether, when, or how to disclose an FASD to others. Parents may choose not to disclose to teachers or neighbors that a child has an FASD in order to avoid negative judgments. Concerns about disclosing that a person has an FASD are an added burden for individuals living with FASDs and their families. Health and service providers can counsel a patient or family member to consider and anticipate how disclosures about alcohol use during pregnancy, or FASDs, can impact the person or others before choosing to whom they should disclose. Providers may also assist by participating in the process of disclosing an FASD, if desired, to an individual's teacher or others who will benefit from better understanding FASDs, and helping in the access to resources to support their relationship with the individual or family.

Once individuals with FASDs enter adulthood, they are typically offered adult protections of confidentiality unless they exhibit a lack of decision-making capacity to make their own medical decisions or are in the care of a legal guardian. Health care providers should adapt to challenges that people with FASDs may experience in understanding and making autonomous decisions about their health and medical treatments. This can be done by matching health education and discussions of medical options to the individual's pace and capacity for learning. When appropriate, health care providers may request that a patient with an FASD permit them to share confidential health information with a designated adult family member or advocate. Anticipating challenges in advance can facilitate discussions in which patients may exercise their decision making to the fullest extent possible. Nevertheless, if an adult patient has adequate decision-making capacity (a determination that admits of subjectivity in some cases (Appelbaum, 2007)), American standards of medical ethics require that their preference regarding medical confidentiality and decision making prevail. Indeed, when a patient makes decisions that appear unreasonable, protecting confidentiality may conflict with the principles of helping (beneficence) and avoiding harm (nonmaleficence). Conflicts involving confidentiality and decision-making capacity cannot always be prevented or resolved simply.

II. Legal and policy issues for individuals and families living with FASDs

A. FASDs and the criminal justice system

Meeting the needs of individuals living with FASDs and capitalizing on the opportunities for intervention often requires a coordinated interplay among systems of care. One of the greatest challenges for families living with FASDs is obtaining a medical diagnosis. The lack of an accurate diagnosis early in life can lead to lifelong secondary disabilities, including trouble with the law (Streissguth, Barr, Kogen, & Bookstein, 1996). Health care providers, regardless of their discipline or practice setting, may encounter patients with FASDs who are experiencing medical or emotional issues related to legal problems.

Medical and allied health practitioners may have a patient diagnosed with a condition along the continuum of FASDs who has been charged with a crime. A provider may also have a patient with an FASD who has been victimized. In both examples, the individual's medical history could be relevant and the provider may interact with the patient's legal counsel if the disability becomes a consideration during judicial proceedings.

Individuals with FASDs are at greater vulnerability than the general population, and often become engaged with the criminal justice system as either offenders or victims. Many individuals with FASDs have neurobehavioral deficits, including lack of impulse control, susceptibility to exploitation and manipulation, impaired ability to recognize social or physical risk, and impaired ability to read social cues. They may also have trouble with "cause and effect" relationships that prevent a conscious understanding of appropriate behavior or the ability to conform to social customs and the laws of society (Edwards & Greenspan, 2010). As a result, a disproportionate percentage of adults, young adults, and even adolescents with FASDs are arrested, convicted, and confined for criminal behavior (Burd, Selfridge, Klug, & Bakko, 2004). Similarly, many are victimized by perpetrators, or become victims of the justice system because they naively admit to crimes they did not commit or are unable to advocate effectively in their own defense.

The neurobehavioral disorders associated with FASDs help to explain why so many individuals encounter trouble with the law. In fact, a significant proportion of individuals with FASDs are only identified with the disability upon entry into the judicial system. This illuminates the importance of education about this condition across law enforcement, courts, and correctional systems if individuals with FASDs are to be afforded fair and appropriate adjudication. Education is critical due to significant misconceptions about FASDs in the justice system as shown in Figure 7.1. (Wartnik & Carlson, 2011)

Figure 7.1. Myths about FASDs within the Justice System

- FASDs are temporary conditions.
- FASDs are conditions lacking in objective findings.
- FASDs are conditions lacking scientific support.
- FASDs are conditions created by lawyers and mental health providers to excuse criminal behavior.
- FASDs cannot be diagnosed without direct evidence that the mother drank during pregnancy.
- Because alcohol exposure in utero results in permanent brain damage, individuals so afflicted cannot be helped and, thus, need to be incarcerated in order to protect the public.

Source: Wartnik, A., & Carlson, S. (2011). A judicial perspective on issues impacting the trial courts related to fetal alcohol spectrum disorders. *Journal of Psychiatry & Law*, 39(1), 73-119.

The University of Washington's FASD Legal Issues Resource Center describes three cardinal issues likely to affect an individual with an FASD in a judicial proceeding:

1) Difficulty grasping the distinction between reality and fiction, thus impairing the individual's ability to assist their legal counsel in evaluating and responding to testimony;
2) Problems with cause and effect processing that may interfere with the individual's ability to evaluate counsel's strategic advice; and
3) An inability to adequately follow the interchanges in a courtroom proceeding (Kelly, 2003).

Some individuals with FASDs are more likely to encounter the police than participate in judicial proceedings. The University of Washington developed a card that individuals with FASDs can present to the police explaining their disability. The purpose of the card is to protect the individual from providing a false confession and to defer questioning until a parent, attorney, advocate, or other support person can be present. The two sides of the card, as modified by the FAS Community Resource Center, are shown in Figure 7.2.

Figure 7.2.   Identification Card for Persons with FASDs

MEDICAL INFORMATION FOR POLICE

I have a Fetal Alcohol Spectrum Disorder, a birth defect that causes brain damage. Please contact the person listed on the back of this card.

Because of this birth defect, I may have difficulty understanding my legal rights. I could be persuaded to admit to acts that I did not actually commit. I am unable to knowingly waive any of my constitutional rights, including my <u>Miranda</u> rights.

Because of my disability, I do not wish to talk with law enforcement officials except in the presence of and after consulting with an attorney. I do not consent to any search of my person or properly.

For information or assistance regarding:
_____
Please contact:
_____
_____
Doctor or diagnostician:
_____
(Please read the other side of this card.)

Source: FAS Community Resource Center. (n.d.). *ID information card for person with fetal alcohol spectrum disorders.* Retrieved from http://www.come-over.to/FAS/Court/CardPoliceFASD.pdf

Those with FASDs can have difficulty planning activities and can be unable to link their actions to specific consequences. Yet case law finds that individuals with FASDs are often described as capable of planning sophisticated criminal actions (Thiel et al., 2011). Brandy Holmes was convicted and sentenced to death in Louisiana for her participation in a violent crime, with little regard for evidence presented to the court that Ms. Holmes suffers from fetal alcohol syndrome (FAS). (See the Case of Brandy Holmes, Figure 7.3) While this case is an extreme example of the consequences of the maladaptive behavior linked to FASDs for both the individual with an FASD and society, it illustrates that, for the individual with an FASD, the distinction between offender and victim can be blurred.

Figure 7.3.   The Case of Brandy Holmes

In *State of Louisiana v. Holmes*, 5 So.3d 42 (La. S. Ct. 2008), the defendant was alleged to have been involved with her boyfriend in a violent crime and was under consideration for a death sentence. The defendant's mother testified that she had a personal history of daily alcohol abuse while pregnant and named the defendant "Brandy" because that was the drink she liked most during her pregnancy.

Due to the combination of her mother's history of prenatal alcohol use, and Ms. Holmes' facial dysmorphia, cognitive deficits, prior mental health diagnoses, and other considerations indicative of FAS, Holmes' defense counsel presented evidence to demonstrate that she had FAS. A psychologist and a psychiatrist testified that the defendant's condition caused her to have diminished mental capacity that affected her decision-making processes. Nevertheless, the prosecution disregarded this evidence as mitigation stating that it was, "Not only not an excuse, it doesn't mitigate anything." Furthermore, during the sentencing phase of the trial, the prosecution characterized the defendant's behaviors (lack of remorse, inability to care, previous history of violence — all deficits that can be associated with FASDs) as aggravating rather than as mitigating factors (Thiel et al., 2011).

The jury voted unanimously for the death sentence, which was upheld on appeal. The National Organization on Fetal Alcohol Syndrome (NOFAS) filed an *amicus* brief to the Supreme Court of the United States on behalf of the defendant arguing in part that behaviors associated with her FAS were improperly used against her as aggravating rather than mitigating factors. NOFAS also argued that the Supreme Court's holding in *Atkins v. Virginia*, 536 U.S. 304 (2002) prohibiting the execution of mentally retarded individuals as a violation of the Eighth Amendment's prohibition against cruel and unusual punishment, was applicable in *State of Louisiana v. Holmes*. The Supreme Court declined to consider the case.

Source: State of Louisiana v. Holmes, 5 So. 3d 42 (La. S. Ct. 2008)

Some states have recently passed statutes recognizing that, in some instances, a diagnosis of a condition along the continuum of FASDs can be considered a mitigating factor during the sentencing phase of criminal prosecution. While the presence of an FASD does not justify or excuse a criminal act, the disability might have bearing on intent and the capacity for an individual with an FASD to understand their actions. FASD mitigation statutes are an important step toward allowing judges and juries to take into account the disability when considering criminal sanctions.

Ethical and justice issues related to individuals with FASDs facing justice systems are gaining recognition in the United States and internationally (Szetela, 2013). In 2012, the American Bar Association (ABA) passed a resolution that begins,

> "RESOLVED, That the American Bar Association urges attorneys and judges, state, local, and specialty bar associations, and law school clinical programs to help identify

and respond effectively to Fetal Alcohol Spectrum Disorders (FASD) in children and adults, through training to enhance awareness of FASD and its impact on individuals in the child welfare, juvenile justice, and adult criminal justice systems and the value of collaboration with medical, mental health, and disability experts.

FURTHER RESOLVED, That the American Bar Association urges the passage of laws, and adoption of policies at all levels of government, that acknowledge and treat the effects of prenatal alcohol exposure and better assist individuals with FASD" (ABA, 2012).

Initiatives such as the ABA resolution present a compelling directive for preventing and responding to individuals with FASDs who become involved with police, courts, and correctional systems.

B. Victimization of individuals with FASDs

Individuals with FASDs are vulnerable to many forms of victimization. It is not uncommon among vulnerable populations that victimization is misunderstood, minimized, or ignored by families, educators, social service professionals, law enforcement, and the judicial system (Mitchell & Davis, 2009). A physician or other health care provider may be the only individual who recognizes some of the signs and warnings of victimization. Health care providers should have open communication with their patients about their experience, risk, and safety.

According to Streissguth et al. (1991), the cognitive effects and behavioral manifestations of FASDs that have implications for victimization include:

- Impairment in short-term memory and processing speed,
- Poor insight and judgment,
- Attention deficits and a lack of planning skills ,
- Difficulty with abstract thinking, including the concepts of time and space (e.g., personal space),
- A lack of ability to identify dangerous people and situations, and
- Inability to apply a lesson from one setting to another.

Individuals with FASDs also may exhibit impulsivity, inability to distinguish private from public behaviors, and difficulties understanding the point of view of another. Such individuals also may be easily influenced by others, eager to please, and prone to misinterpret social cues, such as facial expressions or body language. Woods, Greenspan, & Agharkar (2011) suspect that aggressive, oppositional, and anti-social behaviors that are often seen in individuals with FASDs may in reality be a reflection of the difficulties they have in their abilities to effectively judge, weigh, and deliberate in making sense of the world.

The combined deficits that people with FASDs experience may lead to difficulties assessing danger, understanding and remembering stranger-safety warnings, and cause-and-effect relationships, thus enhancing vulnerability to victimization (Thiel et al., 2011). Crimes involving sexual victimization are a special category of criminal victimization, and Streissguth et al. (1996)

found that 55-60% of those with FASDs in her study had been sexually victimized. Luckasson (1992) noted that interactions with "protectors" who exploit them, a lack of knowledge on how to protect themselves, and living or working in high-risk environments, increase the vulnerability of individuals with FASDs to victimization. Sobsey and Doe (1991) found that 44% of all offenders against individuals with disabilities made initial contact with their victims as they participated in social services provided for people with disabilities. As a result, many victims with FASDs may not report crimes because they depend on the abuser for their care, as can also be the case when the individual with an FASD is the victim of domestic violence.

Erika Harrell's (2014) analysis of the U.S. Department of Justice's National Crime Victimization Survey (NCVS) found that individuals age 12 and over with disabilities experienced approximately 1.3 million nonfatal violent crimes (e.g., rape, sexual assault, robbery, aggravated and simple assault) in 2012. The NCVS survey also found that adolescents aged 12-15 with disabilities experienced violence at nearly three times the rate of those without a disability, and for those aged 16-19, the rate was 2.5 times higher. Sullivan and Knutson (2000) found that children with intellectual disabilities were four times more likely to be sexually abused. Baladerian (1999) suggests that crimes committed against individuals with FASDs may be under-reported at a rate of 25-50%.

Physicians and health care providers who fail to recognize FASDs in their patients may inadvertently contribute to what Thiel et al. (2011) describe as *silent victimization*. They define silent victimization as experiences of those with FASDs that may never surface beyond the home, school, or workplace setting. Such victimization may not be criminal in nature, but it can take the form of abuse or neglect of a child and can have lifetime consequences. At the root of this form of victimization is a fundamental failure to identify FASDs and a tendency to ignore a child's cognitive limitations or problems with adaptive functioning. Failure to address the needs of those with FASDs by parents, siblings and other family members, neighbors, and teachers may occur from earliest childhood onward. Children with unrecognized FASDs may be punished for their perceived failures rather than given the familial, educational, and social supports that their disability requires. School children with unrecognized FASDs may experience bullying, name calling, and other forms of abuse. Academic failure and behavioral outbursts in the classroom may reinforce a label that the child with an unrecognized FASD simply does not try their best, is incapable of learning, and is a disciplinary problem. The longer that FASDs are unrecognized, the more often silent forms of victimization will linger throughout childhood and into adulthood.

Not having an early diagnosis of a condition along the continuum of FASDs has led to many wrongful adoption cases, child welfare involvement, and termination of parental rights cases. Children who were prenatally exposed to alcohol should be evaluated in adoption proceedings so that parents and caregivers receive the educational and social supports these children need rather than return to court years later alleging they were not provided information about the child's condition (Thiel et al., 2011). Mitchell and Davis (2009) suggest that when children who have been diagnosed with a condition along the continuum of FASDs or who are suspected of having FASDs are placed in foster care, social workers responsible for monitoring their care should take the necessary extra steps to ensure that the foster families have proper training and the children receive appropriate services.

Individuals with FASDs and their families require support to anticipate, prevent, and respond to potential harms of maltreatment, abuse, and criminal victimization. Efforts to identify and evaluate individuals who may be affected by FASDs are important first steps. This can allow family members, caretakers, and educators to understand the individual's brain differences and advocate for the person to ensure needed support and services. Additionally, diagnosing children with conditions along the continuum of FASDs may prevent future alcohol exposures in birth families. Health care providers should recognize FASD victimization issues and their implications so they can better support the needs of their patients and families living with FASDs.

III. Legal and policy issues in the maternal-fetal relationship

A. Fetal rights and the maternal-fetal relationship

Fetal rights can be considered from ethical and legal perspectives. Two distinct questions address the rights of the fetus in relation to the rights of the woman who carries the fetus:

- What status does our ethical reasoning attribute to the fetus?
- What status do legal precepts and practices attribute to the fetus?

The ethical status of a fetus is sometimes evaluated in terms of whether fetuses have "personhood." Personhood is a concept conferred upon an individual by its possession of select morally relevant characteristics that make it the proper recipient of human rights and obligations (Edwards & Graber, 1988). The relevant characteristics are contested among philosophers and others. Proponents of competing theories consider personhood to begin at varying stages of fetal development, such as at conception, when the fetus develops a heartbeat, when it becomes viable (able to survive outside the mother's body), or at birth when physical separation from its mother occurs. Others posit personhood to begin after birth such as when the capacity for reasoning develops. Fetuses can be regarded as possessing some degree of ethical status before they achieve the full status of personhood. Although the appropriate ethical status of fetuses is not settled, there is general agreement that the well-being of each person starts during fetal development and that proper care for both fetuses and their mothers is critical.

The legal status of fetuses is addressed by federal and state laws. In the United States, fetuses are not given the legal status of "persons," with rare exception. A fetus' legal status is generally subordinate to that of the pregnant woman and might also change over time with continuing development in utero. The concept of expanded fetal rights at the stage of viability is seen in the U.S. Supreme Court ruling in *Roe v. Wade* (1973). This ruling permits states to restrict access to abortions in the third trimester of pregnancy, approximating the time of viability, except to protect the life or health of the woman. Prior to that point, a woman is conferred a right to abortion which states can limit only in the second trimester to protect a pregnant woman's health. States also, to varying degrees, impose civil and criminal protections of fetal life. For example, some states include fetuses, at varying stages of gestation, among those who can be victims of criminal homicide (Linder, 2005).

While a pregnant woman and her fetus can be considered separately in some ethical and legal respects, a woman and her fetus are ordinarily affected by the well-being of each other, possibly for as long as each lives. In cases where the well-being of a fetus and its mother appear to be in conflict, the ethical and legal issues are deeply challenging. Our society continues to struggle to identify a fully satisfactory framework for conceptualizing fetal and maternal status for cases where maternal interests or behaviors might put the fetus at risk. When maternal and fetal interests are distinct, any resolution might compromise the interests of either or both of them.

B. Laws, policies, and precedents on alcohol use by pregnant women

Preventing the harms of prenatal alcohol use carries great ethical urgency, as prevention serves to benefit fetuses throughout their lives and avoid possible disruption and distress to the mother. A common consideration for preventing prenatal alcohol exposure is to physically bar a woman who poses a high risk to her fetus from accessing alcohol during her pregnancy, such as by criminal or civil commitments. For example, the state of Wisconsin has a statute allowing a pregnant woman whose habitual drinking exposes a fetus to substantial risks of physical harm to be taken into custody to undergo involuntary inpatient alcohol treatment (Linder, 2005). Other states have proposed or enacted bills that respond to a woman who exposes a fetus to the harms of alcohol during pregnancy in ways such as requiring involuntary civil commitment of the woman, requiring health practitioners to report newborns demonstrating prenatal exposure, expanding definitions of child neglect to include neonatal harm or prenatal damage to a child, and defining such acts as criminal mistreatment in the first degree (Substance Abuse and Mental Health Services Administration [SAMHSA], 2012).

Previous and related efforts to apply law enforcement measures to restrain women from exposing fetuses to damaging drugs involve cocaine, particularly in the form of crack. A prominent case is *Whitner vs. State of South Carolina* (1997). Cornelia Whitner was charged with criminal child neglect for exposing her fetus to cocaine, residues of which were found in her newborn when he was drug tested after birth. In 1992, she was sentenced to 8 years in prison by a South Carolina court, which found her viable fetus to be protected under the state's child endangerment statute. Her sentence was affirmed in 1997 by the Supreme Court of South Carolina, holding the viable fetus to be a person, and the U.S. Supreme Court declined a petition for writ of certiorari (review of the case). South Carolina is the first state whose law recognizes the viable fetus as a person and accordingly permits criminal prosecution of women for fetal endangerment (Linder, 2005). Since the South Carolina ruling, other states have proposed or enacted legislation to extend the legal rights of persons to fetuses. In 2012, Alabama's Supreme Court issued a decision upholding that "the word 'child' in the chemical-endangerment statute includes all children, born and unborn." Several states have precedents in legal cases or enacted laws that expand criminal codes to include pregnant women who expose a fetus to drugs or, in some cases, alcohol (Calhoun, 2012).

A second prominent case, reviewed by the U.S. Supreme Court, is *Ferguson v. City of Charleston* (2001). In 1989, as a result of concerns about the incidence of cocaine use among pregnant women, a public hospital in Charleston, South Carolina, began to implement a policy of selectively drug testing women who presented for prenatal care or delivery without their informed consent. Initially, women with a positive drug test would be turned over to the police

for arrest without opportunity to seek treatment instead. The policy was modified in 1990 to allow women to avoid arrest if they entered a drug treatment program, attended all counseling appointments, and passed their subsequent drug tests. Ten of the women arrested as a consequence of positive cocaine tests responded by suing the hospital and the state. In 2001, the U.S. Supreme Court ruled in favor of the women, holding that the drug tests were an unconstitutional search because the hospital was acting as an arm of law enforcement without obtaining a search warrant or informed consent before conducting the drug tests. They held, "A state hospital's performance of a diagnostic test to obtain evidence of a patient's criminal conduct for law enforcement purposes is an unreasonable search if the patient has not consented to the procedure" (*Ferguson v. City of Charleston*, 2001). As a precedent, this decision would limit how health care providers at public hospitals can intervene to prevent fetal alcohol exposure as well.

Health care providers and others should stay informed about the laws and policies related to alcohol use during pregnancy to know expected parameters for acting within the law and to inform advocacy of good laws. The National Institute on Alcohol Abuse and Alcoholism maintains an Alcohol Policy Information System (APIS) that tracks key federal and state policies in the United States related to pregnancy and alcohol. Topics addressed are presented in Figure 7.4.

Figure 7.4.   National Institute on Alcohol Abuse and Alcoholism: Alcohol Policy Information System (APIS), Pregnancy and Alcohol, Topics Addressed by State

- Warning Signs: Drinking During Pregnancy: Laws that require warning signs be posted in settings where alcoholic beverages are sold and health care facilities where pregnant women receive treatment.
- Criminal Prosecution: Laws addressing the use of medical test results, such as prenatal screenings or toxicology tests, as evidence in the criminal prosecution of women who may have caused harm to a fetus or a child.
- Civil Commitment: Laws addressing involuntary civil commitment of pregnant alcohol abusers to treatment or involuntary placement in protective custody of the State for the protection of a fetus from prenatal exposure to alcohol.
- Priority Treatment: Laws mandating priority access to public and private substance abuse treatment for pregnant and postpartum women who abuse alcohol.
- Child Abuse/Neglect: Laws that clarify the admissibility of evidence in child welfare proceedings regarding prenatal alcohol exposure as it pertains to allegations of child abuse, child neglect, child deprivation, or child dependence, or proceedings seeking termination of parental rights.
- Reporting Requirements: Laws addressing requirements to report indicators or evidence, such as results from screening or toxicological testing of women or babies, of alcohol use or abuse by women during pregnancy.

Source: National Institute on Alcohol Abuse and Alcoholism. (n.d.) Alcohol Policy Information System. Retrieved from http://alcoholpolicy.niaaa.nih.gov/

A review of state laws and policies within APIS illustrates a wide range of regulations across states on alcohol use during pregnancy. For example, some states require health care providers to report suspicion of certain types of evidence of alcohol use by pregnant women; whereas others states permit reporting at the provider's discretion, and some do not have any laws or policies on this topic. States also require or permit reporting for different purposes, such as referral for assessment and treatment or to child welfare agencies or both (see SAMHSA, 2014, Chapter 2 section on "Addressing Relevant Regulations"). Variations in state policies demonstrate currently unresolved issues about how best to address a woman's self-governance during pregnancy and potential alcohol-related harms to a fetus, and about effective prevention and intervention approaches.

Additionally, 2010 changes to the federal Child Abuse Prevention and Treatment Act (CAPTA) require appropriate referrals to state Child Protective Services (CPS) agencies when a newborn is diagnosed with a condition along the continuum of FASDs (CAPTA, 2010). Although FASDs are seldom recognized in newborns, in such cases this act requires CPS referral as a mechanism to secure "plans for safe care" for the child. According to the ABA, the CAPTA revision specifically is "not intended to have states make prenatal alcohol or drug exposure a category of child abuse or neglect or to make those children subjects of mandatory reporting laws" (Davidson, 2011).

C. Limitations of coercive and punitive approaches

An ethical and effective response to the risks of FASDs must also account for contributing factors in maternal drinking. While health care professionals now recognize that alcohol and drug addiction are illnesses that usually require effective treatment to overcome, beliefs persist that women who abuse alcohol or drugs while pregnant could readily stop and are morally culpable for continued use (Marshall, Menikoff, & Paltrow, 2003). Women ordinarily do not intend to expose themselves and their fetuses to the risks of compulsive and abusive drinking. Alcohol abuse is frequently associated with unresolved medical and mental health problems (Mertens, Lu, Parthasarathy, Moore, & Weisner, 2003) and difficult social circumstances such as sexual, physical, or emotional abuse (Amaro, Fried, Cabral, & Zuckerman, 1990; Rosenbaum, 1997) and economic stress (Sheehan, 1998). Research shows that treatment programs for alcohol and drug abuse that address these underlying factors produce better outcomes (U.S. Department of Health and Human Services, 1999). Threatening and incarcerating women who live with these burdens does not produce a lasting reduction in their risk exposure or the incidence of alcohol or drug abuse (American College of Obstetrics and Gynecology [ACOG] Committee on Ethics, 2005; ACOG Committee on Health Care for Underserved Women 2011).

The ACOG Committee on Ethics provides guidance in their Opinion, *Maternal Decision Making, Ethics, and the Law*, on ethical practices, policies, and laws regarding women who might risk alcohol- or drug-related harm to their fetuses (ACOG Committee on Ethics, 2005). The Committee offers six objections to coercive and punitive responses to these women [see Figure 7.5]. ACOG and a host of organizations, including the American Academy of Pediatrics, the American Medical Association, the American Nurses Association, the American Public Health Association, the National Council on Alcoholism and Drug Dependence, and the March of Dimes, have issued strong concerns or recommendations against punitive approaches. (See

http://advocatesforpregnantwomen.org/Health%20Statements%20re.%20Punitive%20Policies%20NAPW%202015.pdf for statements from these organizations and others.)

Figure 7.5.   Six Objections to Punitive and Coercive Legal Approaches to Maternal Decision Making

1. Coercive and punitive legal approaches to pregnant women who refuse medical advice fail to recognize that all competent adults are entitled to informed consent and bodily integrity.

2. Court-ordered interventions in cases of informed refusal, as well as punishment of pregnant women for their behavior that might put a fetus at risk, neglect the fact that medical knowledge and predictions of outcomes in obstetrics have limitations.

3. Coercive and punitive policies treat medical problems such as addiction and psychiatric illness as if they were moral failings.

4. Coercive and punitive policies are potentially counterproductive in that they are likely to discourage prenatal care and successful treatment, adversely affect infant mortality rates, and undermine the physician-patient relationship.

5. Coercive and punitive policies directed toward pregnant women unjustly single out the most vulnerable women.

6. Coercive and punitive policies create the potential for criminalization of many types of otherwise legal maternal behavior.

Source: American College of Obstetricians and Gynecologists Committee on Ethics. (2005). ACOG Committee Opinion No. 321: Maternal decision making, ethics, and the law. *Obstetrics and Gynecology*, *106*(5 Pt 1), 1127–1137.

A reasonable legal or policy response to drinking during pregnancy should be balanced with responses considered appropriate for other pregnancy behaviors that pose serious and sometimes equally likely risks to the fetus. These include many relatively common pregnancy behaviors, such as tobacco use, poor management of health conditions that pose fetal risks, and becoming pregnant at young or older reproductive ages. Likewise, male behaviors such as exposure to toxins that can damage sperm, might harm the fetus. Indeed, each serious health risk warrants a response specific to its unique causes and solutions. Recognition that risky pregnancy behaviors have not fueled commensurate efforts to restrict and punish individuals as has occurred with pregnant women who use alcohol and drugs serves as a caution to strive for effective and fair FASD prevention strategies (Eckenwiler, 2004).

Punitive laws that are specific to pregnant women present other concerns as well. Autonomy and justice are compromised when unwarranted rules and restrictions are imposed upon women because they are pregnant. When the legal system is used to enforce such restrictions within the relatively short duration of pregnancy, women are at risk of too little time to prepare their cases, and court decisions are likely rendered too late to adequately protect the fetus. Forcing restraint

from alcohol upon individual women may contribute to mistrust of health care providers by pregnant women who are in need of trusted care.

Work towards effective and just laws and policies that will promote healthy outcomes for women and their children calls for critical reflection on complex causes of alcohol misuse, intended and unintended consequences of laws and policies, and underlying ethical principles.

D. The role of the health care provider in addressing alcohol misuse and stigma

Both alcoholism and FASDs remain highly stigmatized disorders. These stigmas impact public perceptions, availability of optimal treatments, and a person's openness to access available treatments. Society frequently places shame and stigma upon the birth mother when a child is diagnosed with an FASD. Unfortunately, most people still believe that the mother "should have known better" and regard her with conscious or unconscious blame. In reality, there are many different reasons why women drink during pregnancy. According to a 2012 survey of 96 members of the National Organization on Fetal Alcohol Syndrome's (NOFAS) Circle of Hope, a program for birth mothers of children with FASDs, top reasons women drank while pregnant include (Mitchell, 2013):

- "I am an alcoholic. I couldn't stop, and was ashamed to look for treatment."
- "I thought using alcohol was safe. My doctor never told me I should not be drinking."
- "I was afraid to look for help. I was afraid I would be arrested and I would lose my children."
- "I didn't know I was pregnant. I stopped as soon as I found out."

The Circle of Hope survey illuminates that, in Mitchell's words, "No pregnant woman drinks in order to intentionally cause lifelong brain damage to her child" (NOFAS, 2014).

Stigma and shame related to alcohol problems can lead to relapse, stress, depression, anxiety, and an escalation in drinking. Faced with the prospect of prosecution, women who drink during pregnancy may deny they have a problem and be reluctant to pursue a diagnosis for their child. Furthermore, stigma is typically one of the major reasons why the majority of children who receive a diagnosis along the continuum of FASDs are placed in adoptive or foster care homes. Although a woman does not have to be an alcoholic to give birth to a child with effects from drinking while pregnant, it is clearly understood that women with alcoholism are the highest risk group for having children with FASDs (Mitchell, 2013).

According to Mitchell (2010) discovering that your child lives with a disability because you drank during pregnancy is a painful realization. Birth mothers may experience significant guilt, shame, and remorse. Indeed, even the term "fetal alcohol" invites suspicion of a woman's pregnancy behavior and informs everyone in the birth family and close community that the mother caused the disability. All the family members may face continuing shame and stigma as well.

Health care providers should be mindful of how stigma can affect families living with FASDs. Women who have alcohol- or drug-exposed pregnancies, suspect their child may have an FASD,

or are going through the diagnostic process for their child need support and encouragement. For birth mothers of children with FASDs, NOFAS's Circle of Hope mentoring program offers women a safe and reassuring environment with other women who share their experiences and have a desire to restore their lives. It is especially beneficial to have support from another woman who has been there (Mitchell, 2010). See: www.nofas.org/COH.

With increasing recognition of their potential roles, health care providers can be key players in reducing stigmas that affect the health and lives of people with FASDs. The stigma around FASDs can be reduced by improved public understanding of how individuals with FASDs are affected and increasing awareness about alcohol misuse. Individuals with FASDs, birth mothers, or any parent of a child with an FASD should never face the added burdens of stigmatization, discrimination, or shame.

E. A public health approach

Education, prevention programs, and support for alcohol abuse treatment are proactive measures to reduce the harms of prenatal alcohol exposure. Health care providers can spread the message to women of childbearing age that "when you drink, your baby drinks," and encourage effective use of contraceptive methods as well as preconception abstinence from alcohol. As Floyd, Decouflé, and Hungerford (1999) state, "Public health measures needed to reduce these potentially harmful exposures include alcohol assessment, education, and counseling for women of childbearing age, with referral sources for problem drinking, and family planning services for pregnancy postponement until problem drinking is resolved." Many women still do not recognize the dangers of alcohol to a fetus, and social and cultural norms often tolerate or even encourage drinking during pregnancy.

Health care providers are often reluctant to address alcohol use with their female patients, expressing barriers such as lack of training, discomfort talking about women's alcohol use during pregnancy, and a lack of time during health visits (Gahagan et al., 2006; Nevin, Parshuran, Nulman, Koren, & Einarson, 2002). Furthermore, a survey by Diekman et al. (2000) found that many obstetricians and gynecologists were not convinced that total abstinence from alcohol use should be recommended for pregnant women. The advice women receive from their physicians and other health care professionals is an important factor in their decision to decrease their substance use (Diekman et al., 2000). Training for health professionals on frank, non-judgmental, and time-effective ways to talk with patients about drinking alcohol during pregnancy will help them and the public become better informed about how to prevent FASDs. By including preventive interventions in their routine practices, health care providers may gain satisfaction in preventing and minimizing health problems before they occur.

For women with alcohol dependence and abuse, prevention messages alone fall short. Health care providers should screen women for alcohol use and offer referral options for women needing specialized treatment (ACOG, 2015). Unfortunately, there are often few treatment options available for pregnant women and women with dependent family members. According to ACOG Committee on Ethics (2005), "Despite evidence-based medical recommendations that support treatment approaches to drug use and addiction, appropriate treatment is particularly difficult to obtain for pregnant and parenting women and the incarcerated."

In contrast with efforts to punish pregnant women with alcohol dependence, a public health approach incorporating prevention and treatment strategies could have a far greater impact. Even if effective, efforts to legally restrain women from exposing fetuses to the harms of alcohol could be imposed, in practice, only on small numbers of women. Also, such efforts would likely begin when a pregnancy is underway and fetal harm might have already occurred. Studies show that pregnant women who use alcohol and drugs want to protect their fetuses and are motivated to make changes (Murphy & Rosenbaum, 1999). Referrals and access to excellent treatment programs that do not pose undue disruptions upon the present needs of women are a constructive direction for preventing the harms of fetal alcohol exposure. Furthermore, such interventions serve to reduce, rather than increase, stigma and shame for women and their children.

Many public health interventions have been implemented across various states. Interventions for FASDs include allocations of funds for prevention, diagnosis, registries, alcohol and drug recovery awareness events, increased access to addiction treatment, signage requirements, and community grants (SAMHSA, 2012).

There are also population-level interventions that have been shown to be effective in reducing alcohol misuse and its related harms, such as increasing alcohol taxes, limiting alcohol sales, and regulating alcohol outlet density (Community Preventive Services Task Force, 2013). These broad-based strategies should not be overlooked even though they are not directly targeting prevention of FASDs. They can help reduce alcohol consumption rates among the population in general, including women of childbearing age. They also have the potential to modify environments that facilitate alcohol misuse and influence societal norms about alcohol misuse.

Health care providers should consider possible FASDs, in both children and parents, when treating families that have had past histories of alcohol misuse or dependence. The research is very clear on the importance of obtaining an accurate diagnosis: the earlier the better for children who have been exposed to alcohol. While broaching a recommendation for an FASD evaluation must be done with sensitivity to the patient and parents, identification allows families to reframe an individual's cognitive and behavioral struggles and move toward understanding and management.

IV. Summary

Health providers seek to provide ethical care for the women, fetuses, and children they serve. When drinking alcohol during pregnancy poses risk to a fetus, providers can express their respect for both the woman and the fetus by working to address the woman's needs so that she might better care for her developing fetus.

Prevention education is a health care provider's first responsibility to reduce FASDs. For women who might not respond to prevention messages because of alcohol dependence or addiction, health care providers and society have an ethical role to facilitate help, both to benefit the woman and her child.

The personal toll on an individual who is living with an FASD, as well as the toll upon his or her family, can be devastating. Ethical care and well-informed and constructive policies and laws must strive for a day when prevention measures are universal, and people affected by FASDs will benefit from the best health practices and the full support of their communities.

Suggested Learning Activities

- Review and discuss the ethical and policy issues outlined in SAMHSA's *FASDs Curriculum for Addictions Professionals* related to "Adult Case Study" (Jim). See http://store.samhsa.gov/shin/content//SMA07-4297/SMA07-4297.pdf (p. 202 of 401, also called page 3:A1 Adult 1).
- Review and discuss the video, "Recovering Hope: Mothers Speak Out About Fetal Alcohol Spectrum Disorders (FASD)." The video addresses questions like: How do birth mothers of individuals with FASDs think about their own alcohol use and its effects? How do people with FASDs think about their disabilities? What kinds of supports and solutions are appropriate? See https://www.youtube.com/watch?v=m7zfJCW9Yco
- Use case studies to generate discussion about ethical, legal, and policy issues.
- Review the PowerPoint Presentation titled "Ethical, Legal and Policy Issues in Fetal Alcohol Spectrum Disorders" (largely paralleling this chapter, designed for a 3-hour session). See http://www.frfasd.org/documents/Szetela.Carey%20Slides.pdf

Advice for Trainers

Addressing ethical, legal, and policy issues with audiences can raise challenging as well as emotional controversies. By engaging audiences with these complex issues, trainers are helping build foundations for progress in well-considered ethics, laws, and policies that affect people with FASDs, their families, and communities. The following strategies can help trainers maintain focus on learning objectives and optimize time-use in sessions.

- Preface a session by reminding the audience that principles of respectful listening and speaking should be used even amidst disagreement.
- Be vigilant in using and encouraging person-first language that respects the individuality of persons with health conditions. For example, instead of a labeling phrase such as "an FASD person" one might say "a person who has an FASD." Similarly, rather than the term, "pregnant alcoholics," one can say "pregnant women who are alcohol dependent." To obtain information on person-first language, please contact the SAMHSA FASD Center for Excellence by clicking fasdcenter1@ngc.com with subject line "Requesting Person First Language PPT." A PowerPoint presentation discussing the importance of utilizing person-first language in all interactions will be e-mailed to you.
- Allow time for all audience members to express their views on sensitive topics. Large groups can express views by:
  - show of hands,
  - polls using "audience clicker" responses, and

- o small-group discussions followed by whole-group discussions, where a group spokesperson swiftly presents one group finding along with a supporting rationale, until each group has been represented at least once.
  - If an audience member begins to dominate a discussion, state the need to move forward and invite the individual to discuss the issue in greater depth after the presentation.
  - If an audience member presents misinformation, support them for raising the topic and provide corrected information. You may say, "That is a commonly held belief, however current research shows …."
  - If an audience member begins to present personal information that may put their or another person's confidentiality at risk, suggest that they discuss the issue with you privately (without violating an individual's confidentiality) after the session.
  - If asked a question you are unsure about, do not guess or speculate on information you do not know. Offer to find more information and respond to the individual or group after you have a correct answer.
  - Use your personal knowledge about people affected by alcohol use during pregnancy and FASDs. Stories help audience members to engage at a personal level.

Being informed about controversies in ethics, law, and policy is important. If divisive issues arise in a group, you may move issues along by saying "this issue remains unresolved, so let's continue to think about it." Trainers should encourage audiences to consider all sides of an issue as they move forward to judge a best resolution. Given the lack of knowledge and misunderstandings related to FASDs and alcohol use during pregnancy, raising awareness with every training is a great step forward.

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Appendix

- Terms Used in This Guide

- Informational Resources

- Curriculum Development Team

Terms Used in This Guide

I. Curriculum Terms

The learning outcomes described in this curriculum development guide are organized by

- Competencies
- Learning goals

Competencies—a set of knowledge, skills, and attitudes that enables a person to perform specific work. Competencies act as organizing principles for a curriculum. The FASD competencies are those that should be demonstrated by professionals to provide quality prevention, diagnostic, and intervention services related to FASDs.

Learning goals—broad statements about what a learner should be able to accomplish following instruction.

II. Terms Related to Prenatal Alcohol Exposure

Several terms have been used over the years to refer to the disabilities on the continuum of possible effects of prenatal alcohol exposure. The following terms are used throughout the curriculum development guide:

Fetal alcohol spectrum disorders (FASDs). This umbrella term describes the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASDs is not intended for use as a clinical diagnosis.

Fetal alcohol syndrome (FAS). A disorder resulting from maternal prenatal use of alcohol. It is characterized by abnormalities in three domains—growth retardation, neurobehavioral abnormalities, and specific facial characteristics. Confirmed maternal use of alcohol might or might not be documented.

Fetal alcohol effects (FAE). In the past, FAE was generally used to describe children who did not have all of the clinical signs of FAS but who had various problems, including growth deficiency, behavioral problems, or problems with motor and speech skills. In 1996, the Institute of Medicine (IOM) proposed the terms alcohol-related birth defects and alcohol-related neurodevelopmental disorder to replace the less specific term FAE.

Alcohol-related birth defects (ARBD). This term describes the physical defects linked to prenatal alcohol exposure, including heart, skeletal, kidney, ear, and eye malformations.

Alcohol-related neurodevelopmental disorder (ARND). This term describes functional or cognitive impairments linked to prenatal alcohol exposure. These include learning difficulties, poor school performance, poor impulse control, and problems with mathematical skills, memory, attention, judgment, or a combination of these.

Alcohol-exposed pregnancy (AEP). This term is used to describe a pregnancy in which the fetus was exposed to alcohol.

Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE). ND-PAE replaces the term ARND and is delineated in the DSM-5 of the American Psychiatric Association. In most clinical settings and for most families, the primary concern is the effect prenatal alcohol exposure has on the brain or central nervous system, and how this will manifest in a child's development, behavior, and mental functioning. ND-PAE is the appropriate mental health diagnosis among the continuum of FASDs that addresses these concerns. In addition to prenatal exposure to alcohol, criteria for ND-PAE include impairments in neurocognition, self-regulation, and two areas of adaptive functioning.

Alcohol Use Disorders (AUD). AUD is a term used in the DSM-5 to reflect the integration of two DSM-IV disorders (alcohol abuse and alcohol dependence) into a single disorder (AUD) that is measured on a continuum with mild, moderate, and severe sub-classifications. The new criteria fall within four overall groups: impaired control, social impairment, risky use, and pharmacological criteria. Although neither tolerance nor withdrawal is necessary for an AUD diagnosis, past history of withdrawal is often associated with a more severe clinical course.

Informational Resources

Centers for Disease Control and Prevention (CDC)
National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities
Fetal Alcohol Syndrome Prevention Team
4770 Buford Hwy., Mail-Stop E-86
Atlanta, GA 30341-4027
Phone: 404-498-6652
E-mail: FASInquiries@cdc.gov
Website: www.cdc.gov/fasd

Substance Abuse and Mental Health Services Administration (SAMHSA)
FASD Center for Excellence
2101 Gaither Rd., Suite 600
Rockville, MD 20850
Phone: 866-STOPFAS (786-7327)
E-mail: fasdcenter@samhsa.hhs.gov
Website: www.fasdcenter.samhsa.gov

SAMHSA Center for Substance Abuse Prevention (CSAP)
Website: www.samhsa.gov/about-us/who-we-are/offices-centers/csap

SAMHSA Substance Abuse Treatment Facility Locator
Website: findtreatment.samhsa.gov/

National Institute on Alcohol Abuse and Alcoholism (NIAAA)
6000 Executive Blvd. #402
Rockville, MD 20892
Phone: 301-443-3860
E-mail: niaaaweb-r@exchange.nih.gov
Web site: www.niaaa.nih.gov

National Organization on Fetal Alcohol Syndrome (NOFAS)
1200 Eton Ct.
Washington, DC 20007
Phone: 202-785-4585; 1-800-66-NOFAS
E-mail: information@nofas.org
Website: www.nofas.org
Note: NOFAS has a directory of national and state resources:
www.nofas.org/resource-directory/

The Arc of the United States
1825 K St.
Washington, DC 20006
Phone: 800-433-5255
E-mail: info@thearc.org
Website: www.thearc.org

American Academy of Pediatrics (AAP)
141 Northwest Point Boulevard
Elk Grove Village, IL 60007-1098
Phone: 847-434-4000
Website: www.aap.org

American Congress of Obstetricians and Gynecologists (ACOG)
409 12th St., SW, P.O. Box 70620
Washington, DC 20024-9998
Phone: 202-638-5577
Website: www.acog.org

March of Dimes
1275 Mamaroneck Ave.
White Plains, NY 10605
Phone: 914-997-4488
Website: www.marchofdimes.com

Curriculum Development Team

Competency Authors

Competency I: Foundation

Joyce Hartje, PhD
University of Nevada, Reno, Center for the
Application of Substance Abuse
Technologies

Alexandra Edwards, MA
University of Alaska Anchorage, Center for
Behavioral Health Research & Services

Carolyn Edney, MSW
University of Nevada, Reno, Center for the
Application of Substance Abuse
Technologies

Competency II: Alcohol Use Disorders

Joyce Hartje, PhD
University of Nevada, Reno, Center for the
Application of Substance Abuse
Technologies

Nancy Roget, MS
University of Nevada, Reno, Center for the
Application of Substance Abuse
Technologies

Carolyn Edney, MSW
University of Nevada, Reno, Center for the
Application of Substance Abuse
Technologies

Emilie Cattrell, BA
University of Alaska Anchorage, Center for
Behavioral Health Research & Services

**Competency III: Alcohol Screening and
Brief Intervention**

Georgiana Wilton, PhD
University of Wisconsin School of Medicine
and Public Health

Leigh Tenkku Lepper, PhD, MPH
University of Missouri School of Social
Work

Sandra Gonzalez, MSSW, LCSW
Baylor College of Medicine

**Competency IV: Biological Effects of
Alcohol on the Fetus**

P. Kevin Rudeen, PhD
University of Oklahoma Health Sciences
Center

G. Bradley Schaefer, MD, FAAP, FACMG
University of Arkansas for Medical Sciences

**Competency V: Screening, Diagnosis, and
Assessment for Treatment Planning**

Yasmin Senturias, MD, FAAP
UNC/Carolinas Medical Center

David Wargowski, MD
University of Wisconsin School of Medicine
and Public Health

Roger Zoorob, MD, MPH, FAAFP
Baylor College of Medicine

Competency VI: Treatment Across the Life Span for Persons with Fetal Alcohol Spectrum Disorders

Leigh Tenkku Lepper, PhD, MPH
University of Missouri School of Social Work

Georgiana Wilton, PhD
University of Wisconsin School of Medicine and Public Health

Joy Doll, OTD
Creighton University Medical Center

Yasmin Senturias, MD, FAAP
UNC/Carolinas Medical Center

Kathleen Mitchell, MHS, LCADC
National Organization on Fetal Alcohol Syndrome

Joanne Weinberg, PhD – University of British Columbia, Department of Cellular & Physiological Sciences

Competency VII: Ethical, Legal, and Policy Issues

Carolyn Szetela, PhD
Meharry Medical College

Kathleen Mitchell, MHS, LCDAC
National Organization on Fetal Alcohol Syndrome

Tom Donaldson
National Organization on Fetal Alcohol Syndrome

Robert Levine, MD
Meharry Medical College

Danny Wedding, PhD, MPH
American University of Antigua School of Medicine

Reviewers

Fetal Alcohol Syndrome Prevention Team
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

Jacquelyn Bertrand, PhD
Nancy Cheal, PhD, MS
Elizabeth Dang, MPH
Clark Denny, PhD
Catherine Hutsell, MPH
Lela McKnight-Eily, PhD
Megan Reynolds, MPH
Natasha Singh, MPA
Mary Kate Weber, MPH

Consultants

Susan Baker, MPH
Public Health Consultant

John Higgins-Biddle, PhD
Carter Consulting, Inc.