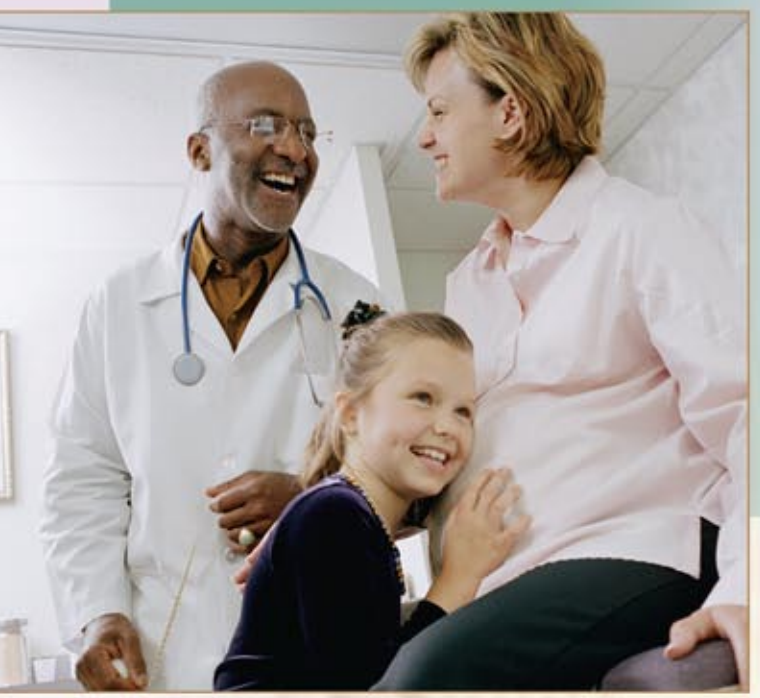
Fetal Alcohol Spectrum Disorders

Competency-Based Curriculum Development Guide

for Medical and Allied Health Education and Practice



U.S. Department of Health and Human Services

Centers for Disease Control and Prevention

National Center on Birth Defects and Developmental Disabilities

FASD Regional Training Centers

National Organization on Fetal Alcohol Syndrome (NOFAS)

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.

Executive Summary

The *Fetal Alcohol Spectrum Disorders (FASD) Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice* was developed by the FASD Regional Training Centers (RTCs), the Centers for Disease Control and Prevention (CDC), and the National Organization on Fetal Alcohol Syndrome (NOFAS). The purpose of the curriculum development guide is to enhance the knowledge and skills of health care providers to recognize and prevent FASDs. It is for use in developing educational programs and materials in a range of formats based on the needs of learners. The guide is organized by the following types of learning outcomes:

- Competencies—sets of knowledge, skills, and attitudes that enable a person to perform specific work.
- Learning goals—broad statements of what a learner should be able to do after instruction.
- Learning objectives—the specific steps needed to reach the learning goals.

Medical and allied health students and professionals who desire to learn about FASDs have a variety of educational backgrounds and skill levels. While the competencies and goals are the same for all learners, the learning objectives have been tailored to meet varying needs and skills.

The seven competencies for the curriculum are as follows:

I. Demonstrate knowledge of the historical, biomedical, and clinical background of fetal alcohol syndrome (FAS) and other disorders related to prenatal exposure to alcohol, known collectively as fetal alcohol spectrum disorders (FASDs).

II. Provide services aimed at preventing alcohol-exposed pregnancies in women of childbearing age through screening and brief interventions for alcohol use.

III. Apply concepts and models of addiction to women of childbearing age, including those who are pregnant, to provide appropriate prevention services, referral, and case management.

IV. Describe the effects of alcohol on the developing embryo and fetus.

V. Screen, diagnose, and assess infants, children, adolescents, and adults for FAS and other prenatal alcohol–related disorders.

VI. Provide long-term case management for persons with FASDs.

VII. Recognize ethical, legal, and policy issues related to FASDs.

Within each competency, specific learning objectives have been designated for three skill levels:

Level 1—Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2—Medical and allied health practitioners who need to use the information to provide services.
Level 3—Medical and allied health professionals who educate and train other professionals about FASDs.

Educators or trainers can select the appropriate goals and objectives with which to develop an educational program based on the level that is appropriate for the participants' learning needs and current skill levels, along with university or organization criteria.

Introduction

Prenatal alcohol exposure is one of the leading preventable causes of birth defects and developmental disabilities. Effective strategies are needed both for diagnosing and treating children with fetal alcohol syndrome (FAS) or other prenatal alcohol–related conditions (known collectively as fetal alcohol spectrum disorders or FASDs), and for identifying women at risk of having an alcohol-exposed pregnancy and intervening to prevent adverse outcomes. Since FAS was identified approximately 30 years ago, significant advancements have been made in diagnosis, surveillance, prevention, and intervention, but a substantial amount of work remains.[1]

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 funding legislation, Congress mandated that 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, would

- 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 the national initiative, in 2002 CDC funded four FASD Regional Training Centers (RTCs) to develop, implement, and evaluate educational curricula for medical and allied health students and practitioners. The RTCs, funded from 2002 to 2008 were[2]:

- Midwestern FASD Regional Training Center (a collaboration among Saint Louis University, the University of Missouri-Columbia, and St. Louis Arc)
- Northeastern FASD Regional Training Center (based at the University of Medicine and Dentistry of New Jersey)
- Southeastern FASD Regional Training Center (a collaboration among Meharry Medical College, Morehouse School of Medicine, and Tennessee State University)
- Western FASD Regional Training Center (based at the University of California, Los Angeles)

1 Centers for Disease Control and Prevention (2002). National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect—Defining the National Agenda for Fetal Alcohol Syndrome and Other Prenatal Alcohol-Related Effects. *Morbidity and Mortality Weekly Report Recommendations and Reports 51*, RR14, 9-12.

2 Contact information for the RTCs is provided in the Appendix.

The Curriculum Development Guide: An Overview

The RTCs, in collaboration with CDC and the National Organization on Fetal Alcohol Syndrome (NOFAS), developed the *FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice*. 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. These competencies are as follows:

I. Demonstrate the historical, biomedical, and clinical background of fetal alcohol syndrome (FAS) and other disorders related to prenatal exposure to alcohol, known collectively as fetal alcohol spectrum disorders (FASDs).

II. Provide services aimed at preventing alcohol-exposed pregnancies in women of childbearing age through screening and brief interventions for alcohol use.

III. Apply concepts and models of addiction to women of childbearing age, including those who are pregnant, to provide appropriate prevention services, referral, and case management.

IV. Describe the effects of alcohol on the developing embryo and the developing fetus.

V. Screen, diagnose, and assess infants, children, adolescents, and adults for FAS and other prenatal alcohol–related disorders.

VI. Provide long-term case management for persons with FASDs.

VII. Recognize ethical, legal, and policy issues related to FASDs.

Medical and allied health students and professionals who desire to learn about FASDs have a variety of educational backgrounds and skill levels. Therefore, learning goals and objectives for each competency have been categorized according to those skill levels:

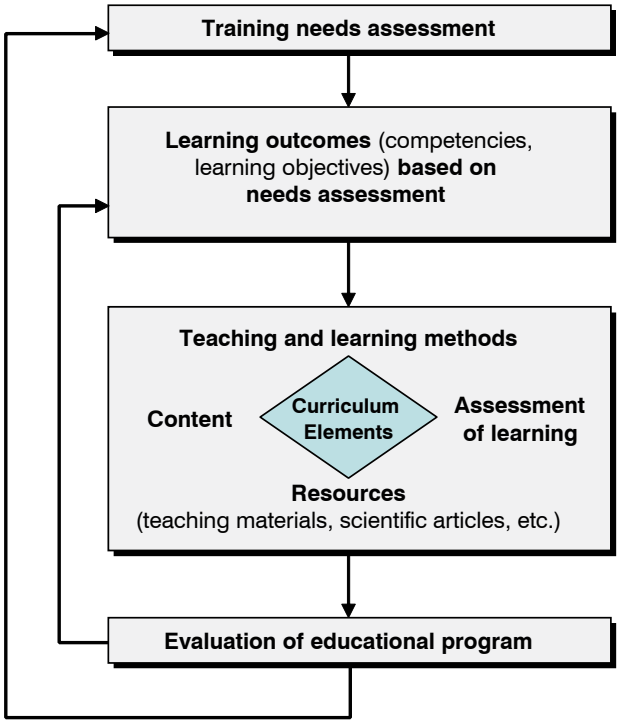
Level 1—Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.

Level 2—Medical and allied health practitioners who need to use the information to provide services.

Level 3—Medical and allied health professionals who educate and train other professionals about FASDs.

Although these skill levels are numbered 1, 2, and 3, they are not meant to represent a hierarchy of skills. Rather, they indicate how they will be used (i.e., knowledge, practice, teaching). Persons who teach or organize courses, workshops, and other educational programs will determine the level at which they will present each competency based on the participants' learning needs and university criteria, if applicable.

Model for Developing This Guide



The FASD curriculum development guide was developed using an outcomes-based model. First, the developers conducted a training needs assessment. They hosted subject matter expert forums, reviewed the literature, and examined existing curricula and health care provider surveys. Based on findings from the needs assessment, they developed learning outcomes by answering the question: "What will the learners know, be able to do, and/or value when they have completed their training?" The learning outcomes are expressed in terms of competencies, goals, and learning objectives.

The learning outcomes guide the content of the curriculum for each competency. The RTCs also identified teaching and learning methods, methods of assessment of individual learners, and resources related to the outcomes of each learning outcome. Curriculum elements can be combined to create educational experiences 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
- CD-ROMS
- Video conferences
- Independent study opportunities

The outcomes-based model also includes an evaluation component. Although it is listed last in the conceptual framework, it is an ongoing process rather than a final step. Evaluation should be considered from the beginning of the process. In this model, evaluation has two parts: (a) evaluation of whether learners achieve the learning outcomes; and (b) evaluation of the effectiveness of the overall curriculum and its long-term impact (e.g., do health providers improve their screening of women for alcohol use?). Evaluation helps in determining the need for additional training needs assessment or refinement of learning outcomes. Such changes, in turn, impact the entire curriculum design.

Using the FASD Curriculum Development Guide

Each chapter 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 readings.
- Chart of learning goals and learning objectives for the competency.

Learning objectives are detailed by their skill level, as discussed previously. Further, each objective is designated as attitude-based (A), knowledge-based (K) or skill-based (S). Knowing the type of objective(s) being taught will help the instructor to select the most appropriate teaching strategies to help learners achieve that objective. An appendix provides supplemental information and resources that can be helpful in developing curricula and other educational materials on FASDs.

Following are two examples of how the *FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice* could be used.

Example 1—FASD component in medical school curriculum
A medical school wants to add the topic of FASDs to its first-year curriculum. Five hours have been allotted within an existing class to present the information. Teaching staff decide to focus on Competency I—Demonstrate the historical, biomedical, and clinical background of fetal alcohol syndrome (FAS) and other prenatal alcohol-related disorders, known collectively as fetal alcohol spectrum disorders (FASDs). This is a foundational competency, encompassing basic information that is critical for all health care providers. Next, staff members select a combination of attitude-based, knowledge-based, and skills-based objectives from the skill level 1 list, as these are geared toward students. Finally, teaching methods and supplementary resources are selected from the "Strategies and Resources for Teaching" section of appendix of this guide. All elements are adapted to fit the needs of the students and the school. After the information has been presented in class, teaching staff use the evaluation section in "Strategies and Resources for Teaching" to determine whether students achieved the learning objectives.

Example 2—FASD training session at a professional conference
A state association of family physicians wants to incorporate at its annual conference a 1-hour session about how to improve screening and referral of children who might have FAS or a related condition. The trainer focuses on Competency V—screen, diagnose, and assess infants, children, adolescents, and adults for FAS and other prenatal alcohol-related disorders—and selects learning objectives that fall under skill level 2, as this training is intended for practitioners. Next, the trainer selects appropriate teaching strategies and techniques to facilitate the achievement of the objectives by the learners. Finally, from the appendix of this guide, the trainer copies the information about the FASD Regional Training Center in the area as a resource for conference participants who want more information.

A Note About Terminology

Throughout the curriculum development guide, the terms FAS and FASDs are both used. FAS is used when referring to diagnostic criteria specifically for fetal alcohol syndrome and when discussing surveillance because, to date, most surveillance data are for FAS specifically. FAS is also used when referring to older efforts or titles that occurred before the term FASDs was introduced. The term FASDs, defined in 2004, is used when discussing the full range of effects that can occur from drinking during pregnancy and when discussing individuals who are living with these effects. This term is also used when discussing prevention because efforts are underway to prevent alcohol-exposed pregnancies and the full range of effects, or spectrum, that can occur from drinking during pregnancy. For more information about terminology and definitions, see the Appendix.

Competency I: Foundation

The health care student or provider will be able to demonstrate knowledge of the historical, biomedical, and clinical background of fetal alcohol syndrome (FAS) and other disorders related to prenatal exposure to alcohol, known collectively as fetal alcohol spectrum disorders (FASDs).

This is a foundational competency for the entire curriculum. This competency should be addressed in all settings and for all audiences unless they have prior knowledge of the content related to this competency.

Learning Goals

(Learning objectives for each goal can be found at the end of this chapter.)

I-A Describe the basic biomedical foundation of FAS.
I-B Explain the basic clinical issues related to FASDs.
I-C Provide an overview of the epidemiological and psycho-social-cultural aspects of FASDs

Content Outline for Competency I

I. Basic biomedical foundation
- A. Scope of the issue
- B. Recognition of the issue
- C. Effects of alcohol on the developing embryo and fetus
- D. Characteristics of FAS

II. Clinical issues
- A. Prevention of alcohol-exposed pregnancies
- B. Screening and diagnosis of persons with FAS
- C. Treatments and therapies for persons with FASDs

III. Epidemiological and psycho-social-cultural aspects of FASDs
- A. Prevalence of FASDs
- B. Monitoring prenatal alcohol exposure
- C. Costs of FASDs
- D. Psychosocial and cultural effects

Also included in this chapter are:

- Suggested learning activities.
- References and helpful websites.
- Chart of all learning goals and objectives for this competency.

I. Basic Biomedical Foundation

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A. Scope of the Issue

Alcohol use is an entrenched institution in the United States and many other countries. Worldwide use and subsequent abuse of alcohol is increasing. In the United States, as many as 74% of individuals over the age of 15 years consume alcohol (Babor, 2003). The amount of alcohol consumed by each person is increasing; among people who report binge drinking, the number of binge episodes has increased (Babor, 2003). Further, alcohol consumption and binge drinking are being initiated at a younger age, a key predictor of adult alcohol abuse and dependency (NIAAA, 2000).

Historically, women have been less likely to drink alcohol than men; however, that discrepancy is quickly disappearing. More than half of all women of childbearing age (18–44 years of age) report some alcohol use, and one in eight reports binge drinking in the past month. Many of these women are sexually active and often do not take effective measures to prevent pregnancy. These women are at high risk for an alcohol-exposed pregnancy (AEP) as they might continue drinking early in pregnancy at levels that are harmful to the fetus (Centers for Disease Control and Prevention [CDC], 2002a; Department of Agriculture & U.S. Department of Health and Human Services, 2000; Floyd et al., 2007; Tsai & Floyd, 2004).

Although most women reduce alcohol consumption after learning that they are pregnant (CDC, 1995), in the United States, 10% of pregnant women report consuming any alcohol and 2%–4% report binge drinking (Tsai & Floyd, 2004; Substance Abuse and Mental Health Services Administration [SAMHSA], 2002). In these findings, binge drinking was defined as consuming five or more drinks on any one occasion. More recently, the definition of binge drinking for women has been changed to four or more drinks on any one occasion (NIAAA, 2005).

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 are lifelong and serious. Children born with prenatal alcohol exposure might have a range of problems, from subclinical effects to full fetal alcohol syndrome (FAS), conditions that result in significant morbidity and mortality (NIAAA, 2000).

B. Recognition of the Issue

Paul Lemoine of France first described the effects of prenatal alcohol exposure in the medical literature in 1968. This sentinel article was later translated to English (Lemoine, Harousseau, Borteyru, & Menuet, 2003).

The most important breakthrough in the understanding and documenting of FAS in the United States came through the work of Drs. Jones and Smith and their colleagues (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 children was a

distinctive constellation of physical abnormalities, growth retardation, central nervous system 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). This book describes the author's experiences with his adopted son, Adam, who had FAS. He explained the negative consequences of prenatal alcohol exposure in a way that could be understood by the general public, rather than by medical professionals with particular specialties.

As researchers have looked at cases historically diagnosed as mental retardation and related conditions, they have found that many might have actually been cases of FAS and other alcohol-related effects. A striking example of this fact was presented by Karp and his colleagues in 1995. They looked at work done by Henry Goddard, an American psychologist and eugenicist. In 1912, Goddard 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. This 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 suggests that FAS and prenatal alcohol exposure better explain the Kallikak family history of disabilities than does genetics (Goddard, 1912; Karp, Quazi, Moller, Angelo, & Davis, 1995).

In 1981, the U.S. Surgeon General issued a public health advisory warning that alcohol use during pregnancy could cause birth defects (Food and Drug Administration, 1981). This warning was reissued by the Surgeon General in 2005 (Office of the Surgeon General, 2005).

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 lifelong. 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: Office of the Surgeon General, U.S. Department of Health and Human Services. (2005). *Advisory on alcohol use in pregnancy*.

C. Effects of Alcohol on the Developing Embryo and Fetus

All maternal systems are vulnerable to alcohol. A developing embryo or fetus, which relies on the mother's systems, is equally vulnerable. Although the adverse mechanisms of prenatal alcohol exposure are not completely understood, the harmful effects are evident. As a pregnant woman consumes alcohol and her blood alcohol level rises, the alcohol freely crosses the placenta. The embryo or fetus is exposed to the same blood alcohol levels as the mother. However, the baby's

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.

Discussions about drinking during pregnancy most often center on the amount of alcohol consumed. Some individuals, including some clinicians, believe that small amounts pose no risks. However, as reflected in the Surgeon General's advisory, there is no known safe amount of alcohol during pregnancy (Goodlett & West, 1992). Maternal intake of about one drink/day or more is associated with reduced birth weight and intrauterine growth restriction, spontaneous abortion, preterm delivery, and stillbirth. Furthermore, varying degrees of prenatal alcohol exposure have been found to be associated with disrupted neuropsychological functions like attention, learning and memory, visual perceptual and visual motor skills, language, and executive functions (Bertrand et al., 2004).

Another misconception is that some types of alcohol are okay or less harmful than others; specifically, beer or wine is viewed as acceptable or less risky than hard liquor. This belief is false. A 12-ounce can of beer containing 5% absolute alcohol (aa) has the same amount of alcohol as a 5-ounce glass of wine (12% aa), a 4-ounce glass of fortified wine (15% aa), or a 1.5-ounce shot of hard liquor or spirits (40% aa) (NIAAA, 2005).

Finally, no period of pregnancy appears to be safe for drinking. Damage can occur at any point after conception. Major morphological abnormalities caused by alcohol can occur in the first trimester. In the second trimester, there is an increased risk of spontaneous abortion. In the third trimester rapid fetal growth makes this a vulnerable period for height, weight, and brain growth. The brain can be affected during all trimesters (Goodlett & West, 1992).

Areas in the fetus known to be affected by alcohol include skeletal structures, organs, central nervous system, and related rates of growth. Alcohol interacts with the developing central nervous system through multiple actions, including (NIAAA, 2000):

- Interfering with the normal proliferation of nerve cells.
- Increasing the formation of cell-damaging molecular fragments (free radicals).
- Altering the cell's ability to produce or regulate cell growth, division, and survival.
- Impairing the development and function of cells that guide the migration of nerve cells to their proper places (astrocytes).
- Interfering with the normal adhesion of cells.
- Altering the formation of axons.
- Altering cell membranes.
- Altering the pathways of biochemical or electrical signals within cells.
- Altering the regulation of calcium levels in the cell.
- Altering the expression of certain genes.

No single mechanism can explain all the harmful effects of alcohol on the developing fetus. The 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, eligibility for services).

Competency IV provides an in-depth description of the biological effects of alcohol on the developing fetus.

D. Characteristics of FAS

The characteristics of FAS have been well documented. They include dysmorphia (especially facial features), growth restriction, and central nervous system (CNS)–related abnormalities (Jones, 2006).

Dysmorphic features are outward signs of abnormal cell development and processes during the implantation, embryonic, or fetal states of gestation. They are most often clues, rather than formal diagnoses. The cardinal dysmorphic features of FAS are (a) short palpebral fissures, (b) thin vermillion border (upper lip), and (c) smooth philtrum. Additional associated facial features include a flattened midface, epicanthal folds, low nasal bridge, minor ear abnormalities, and micrognathia. Nonfacial dysmorphia include cardiac anomalies, joint abnormalities, ear anomalies, ptosis, hypoplastic nails, pectus carinatum or excavatum, and altered palmar flexional crease patterns (i.e., hockeystick crease) (Bertrand et al., 2004).

Growth is affected on several levels. Both pre- and postnatal growth is limited. The primary parameters of growth that need to be impaired to meet the growth retardation criteria for a diagnosis of FAS are height, weight, or both. Typically, children with FAS are small for their gestational age. They are typically of short stature, are underweight (failure to thrive), and have height or weight discrepancies. Multiple organic factors can lead to growth deficiencies (e.g., disruption of endocrine function leading to poor weight gain) (Bertrand et al., 2004).

Fetal alcohol exposure affects all regions of the brain, though some regions appear more vulnerable than others. Through magnetic resonance imaging and additional technology, researchers have been able to document an overall reduction in brain size in children with FAS. Further, 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 taken advantage of, immaturity, superficial interactions, inappropriate choice of friends, poor social cognition) (Bertrand et al., 2004).

Functional abilities vary greatly across individuals with FASDs since there is variation in the dose and timing of exposure as well as postnatal environmental influence, as noted previously. 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).

II. Clinical Issues

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A. Prevention of Alcohol-Exposed Pregnancies

All physicians need to participate in primary prevention efforts regardless of medical specialty. Contributions of the physician include providing information about the dangers of drinking during pregnancy, screening women for risk of an alcohol-exposed pregnancy, and referring women with alcohol problems for appropriate treatment.

Strategies aimed at preventing alcohol-exposed pregnancies include the following:

- **Universal prevention efforts** aim to educate the public about the dangers of alcohol use during pregnancy. Prevention strategies include warning labels on alcoholic beverages, public service announcements, and mass media campaigns.
- **Selective prevention interventions** target individuals or a subgroup of the population who are at increased risk for having an alcohol-exposed pregnancy, meaning all women of childbearing age who drink alcohol. Prevention strategies include screening women for alcohol use and providing brief intervention for women at risk for an alcohol-exposed pregnancy. Alcohol screening instruments include the TWEAK, T-ACE, CAGE, and AUDIT.
- **Indicated prevention interventions** target women at highest risk for giving birth to a child with an FASD, including women who have previously given birth to a child with an FASD or a woman who has a known history of alcohol abuse or dependence. Prevention strategies include alcohol treatment and measures to prevent pregnancy (Hankin, 2002).

Please see Competency II and *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis* (Bertrand et al., 2004) for more information about screening and treatment of women.

B. Screening and Diagnosis of Persons with FAS

Many terms are used to describe the continuum of effects that result from prenatal exposure to alcohol, including fetal alcohol effects, alcohol-related birth defects, and alcohol-related neurodevelopmental disorder. A more recent term that has been introduced is fetal alcohol spectrum disorders (FASDs). It is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects can include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. This term is not intended for use as a clinical diagnosis.

The screening of children and persons with possible effects from prenatal alcohol exposure is an important step in the identification of FASDs. Various health and education professionals often formally and informally screen. The purpose of such screening is to identify triggers—conditions known to be related to the presence of FAS or other related disorders. If enough triggers are present, referral to determine diagnosis is the next step.

Clear diagnostic criteria for FAS and instructions on their use can help health care providers better identify children with this condition. Currently, guidelines for referral and diagnosis are available only for FAS, but work continues to develop such guidelines for other conditions within the spectrum. A diagnosis of FAS is best made within the context of a multidisciplinary assessment of the individual.

The major components of the diagnostic criteria for FAS are:

- **Facial dysmorphia:** smooth philtrum, thin vermillion border, and 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.
- **Central nervous system abnormalities:** Documented structural, neurological, or functional problems in areas associated with prenatal alcohol exposure (e.g., attention, math, executive functioning).

To receive the diagnosis of FAS, an individual must have documentation of all three components of the diagnostic criteria (i.e., dysmorphia, growth deficits, and a CNS abnormality). In addition, the diagnosis should be characterized by the information available about exposure history as either (a) confirmed prenatal alcohol exposure or (b) unknown prenatal alcohol exposure.

Because individual features are not unique to any specific syndrome, a process of differential diagnosis is essential for assessing all components of the diagnostic criteria. Other syndromes also exhibit facial dysmorphic traits that overlap with FAS, and there are some syndromes in which a constellation of features gives a "gestalt" that is similar to that of FAS. These syndromes should particularly be considered when completing the differential diagnosis: Aarskog syndrome, Williams syndrome, Noonan syndrome, Dubowitz syndrome, Cornelia de Lange syndrome, toluene embryopathy, fetal dilantin syndrome, fetal valproate syndrome, and maternal PKU fetal effects (Bertrand et al., 2004). Many genetic syndromes have growth issues related to their diagnosis. And most importantly, many environmental factors can lead to growth problems, including poor nutrition, abuse and neglect, or even depression.

The most challenging component for differential diagnosis is CNS abnormalities. Individuals with many other conditions have functional deficits that are similar to those of FAS at a general level, but they are not completely identical. For example, both children with FAS and children with attention-deficit/hyperactivity disorder (ADHD) have diagnosable attention problems, but children with FAS have difficulty with flexibility of attention and encoding information, whereas children with ADHD have problems with focus and sustaining attention. Even more challenging is distinguishing between presenting CNS abnormalities resulting from prenatal alcohol exposure and similar CNS abnormalities resulting from psychosocial factors (e.g., abuse and neglect, disruptive care giving, or lack of opportunities).

In addition to establishing the presence of FAS, a complete diagnosis needs to identify and specify other disorders that can co-exist with FAS. These include autism, conduct disorders, oppositional defiant disorder, anxiety disorders, adjustment disorders, sleep disorders, and depression (Bertrand et al., 2004).

Please see Competency V and *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis* (Bertrand et al., 2004) for more information about screening, diagnosis, and assessment of FAS.

C. Treatments and Therapies for Persons with FASDs

Diagnosis is part of a continuum of care that identifies and facilitates appropriate health care, education, and community services as needed. Early intervention is critical in the treatment of any disorder. This means providing treatment not only for young children, but also for older individuals as soon as problems are identified. In addition, some protective factors against secondary conditions have been identified: a stable and nurturing home environment during the school years, early diagnosis (before 6 years of age), absence of exposure to violence, consistency in caregivers, and eligibility for social and educational services (Streissguth, Barr, Kogan, & Bookstein, 1996).

Because any individual with an FASD is the product of a unique interaction of dose and timing of alcohol exposure as well as experiences, the service needs of affected individuals and their families can differ significantly. However, some general areas of service and specific services have been identified that are universally beneficial, including a nurturing and structured care giving environment, parent and service provider education about FASDs, and a thorough multidisciplinary evaluation to identify individual strengths and weaknesses (Streissguth, 1997). Families and caregivers are essential in the treatment planning process (Mitchell, 2002).

The heterogeneous nature of persons with FASDs makes an interdisciplinary team approach extremely important. Depending on the needs of the person with an FASD, the treatment team might include a dysmorphologist; geneticist; neurologist; primary care physician; pediatrician; ophthalmologist; ear, nose, and throat specialist; immunologist; plastic surgeon (if cleft lip or palate exists); endocrinologist; gastroenterologist; psychiatrist; psychologist; social worker; special educator; nutritionist; audiologist; speech-language pathologist; occupational therapist; and physical therapist.

Please see Competency VI for information about treatment and case management for persons with FASDs.

III. Epidemiological and Psychosocial and Cultural Aspects of FASDs

Michael Brimacombe, PhD; Yvonne Fry-Johnson, MD; Jacquelyn Bertrand, PhD; Taleria Fuller, PhD; Robert Levine, MD; and Carrie Lee Venable, MS

A. Prevalence of FASDs

CDC reports FAS prevalence rates from 0.2 to 1.5 cases per 1,000 births across various populations in certain parts of the United States (CDC, 2002b). These rates are comparable to or greater than other common developmental disabilities such as Down syndrome or spina bifida (May & Gossage, 2001). Of the approximately 4 million infants born each year, an estimated 1,000 to 6,000 will be born with FAS (Bertrand et al., 2004). Some researchers have estimated the rates of the full range of FASDs to be as high as 9 or 10 per 1,000 live births (May & Gossage, 2001; Sampson et al., 1997). This translates to about 40,000 alcohol-affected births per year in the United States (Lupton, Burd, & Harwood, 2004).

Disadvantaged groups, American Indians/Alaska Natives, and other minorities have been documented to have prevalence rates as high as 3 to 5 cases of FAS per 1,000 children (Sampson et al., 1997). Among children in foster care, the prevalence rate for FAS is 15 cases per 1,000 children (Astley, Stachowiak, Clarren, & Clausen, 2002). Finally, among individuals in the juvenile justice system, more than 200 per 1,000 20% were found to have FAS or a related disorder (Fast, Conry, & Loock, 1999).

As noted previously, alcohol consumption is a worldwide public health issue. As would be expected, countries that have high rates of alcohol consumption also have high rates of FAS. In Russia, which has very high rates of alcoholism, prevalence of FAS among children in orphanages is estimated to be 15 cases per 1,000 (Miller et al., 2006). In South Africa, the production and sale of alcohol is promoted as an important economic activity. South Africa has the highest reported birth prevalence for FAS with reports of 41 to 46 cases per 1,000 live births. Rates of FAS are particularly high in rural areas of South Africa where many workers are involved in wine production (May et al., 2007; Viljoen et al., 2005).

Although true differences in rates for FAS certainly exist, some of the variation might be due to challenges in estimating FAS prevalence. First, no specific and uniformly accepted diagnostic criteria have been available for FAS. Second, FAS diagnosis is based on clinical examination of features, but not all children with FAS look or act the same. Third, many primary care providers lack knowledge of and have misconceptions about FAS. Fourth, there are no diagnostic criteria to distinguish FAS from other prenatal alcohol-related conditions (Bertrand et al., 2004). Finally, studies in the United States have used a record review methodology, which clearly underestimates the prevalence of the disorder. This is demonstrated by a recent study in Italy, which used a direct evaluation method for school children and found rates of 4 to 7 cases per 1,000 children (May et al., 2006).

Additional information and references are available in *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis* (Bertrand et al., 2004).

B. Monitoring Prenatal Alcohol Exposure

As noted previously, in the United States, 10% of pregnant women report consuming any alcohol, and 2%–4% report binge drinking (Tsai & Floyd, 2004; Substance Abuse and Mental Health Services Administration [SAMHSA], 2002). More than half of all women of childbearing age (18–44 years of age) report some alcohol use, and one in eight reports binge drinking in the past month (CDC, 2002a; Tsai & Floyd, 2004).

The risk of a woman giving birth to a child with an FASD depends on multiple factors, such as the pattern, volume, timing, and duration of alcohol use. Additional maternal risk factors might include age, race, ethnicity, socioeconomic status, nutrition, alcohol metabolism, genetic sensitivity to alcohol, and possible interactions among these factors (Tsai, Floyd, Green, & Boyle, 2007).

C. Costs of FASDs

The costs of FASDs are beginning to be understood and formally addressed. To date, cost estimates are only available for FAS. Annual costs associated with FAS in the United States are estimated to be approximately $4 billion (Lupton et al., 2004). In 2002, the estimated lifetime cost for one individual with FAS was $2 million. This is an average for all people with FAS. Those with severe problems, such as profound mental retardation, have much higher costs (Lupton et al., 2004).

D. Psychosocial and Cultural Effects

Like any medical condition, FASDs substantially increase the burden on society and its resources. FASDs are considered birth defects and developmental disabilities, and persons with these conditions have increased health care needs from birth through adulthood. In addition, individuals with FASDs are at very high risk for injury, unintended pregnancy, and sexually transmitted infections.

The most severe impact arises from functional problems, including mental health difficulties, disrupted school and job experiences, trouble with the law, difficulties with independent living, substance abuse, problems with parenting, and more (Bertrand et al., 2004; Streissguth et al., 1996). Everyday needs such as transportation, job assistance, and housing compete within already overburdened social services. Some individuals with FASDs qualify for federal assistance, such as Medicaid, Supplemental Security Income (SSI), and Section 8 Housing subsidies.

FASDs have serious and often devastating effects on the patient and family (Streissguth, 1997). Disabilities are experienced by the affected person from infancy through adulthood. Many families face complex situations and might present with numerous health and social problems. Parents of individuals with an FASD report clinically elevated levels of stress (Paley, O'Connor, Frankel & Marquardt, 2006). FASDs raise unique treatment issues and the need for 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.

Thus, FASDs are a major public health problem with significant costs, both in terms of the long-standing suffering of children and families of all ethnicities, and in marked economic loss of billions of dollars in the United States and societies around the world. However, FASDs and the related increased burdens can be avoided because FASDs are completely preventable.

Competencies III, V, and VI have more information about the impact of FASDs on psycho-social and cultural issues.

Suggested Learning Activities

- Use descriptive case studies to discuss effects of FASDs (see supplemental materials available online).
- Use the "Critical Stages of Development" chart to illustrate fetal development and the effects of teratogens at different stages of development (see Competency IV, Figure 4.1).
- Use the drawing "Facies in Fetal Alcohol Syndrome" from Streissguth & Little (1994) to have groups identify related facial features.
- Use case studies to identify treatment options.
- Lead a discussion of costs of FASDs to individuals and society.
- Have small groups develop a list of challenges in addressing FASDs, then list societal benefits in addressing alcohol use. Have small groups share with the large group to share ideas and generate discussion.

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Websites

Federal Government Sites

- CDC's Fetal Alcohol Spectrum Disorders website: http://www.cdc.gov/ncbddd/fas/
- National Institute on Alcohol Abuse and Alcoholism: http://www.niaaa.nih.gov/
- National Institute on Drug Abuse: http://www.nida.nih.gov/
- Substance Abuse and Mental Health Services Administration, Center for Substance Abuse and Prevention (CSAP): http://prevention.samhsa.gov/
- SAMHSA's FASD Center for Excellence: http://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://depts.washington.edu/fadu/
- Fetal Alcohol Syndrome Diagnostic & Prevention Network, University of Washington: http://depts.washington.edu/fasdpn/

Learning Goals and Related Objectives

Goal I-A: Describe the basic biomedical foundation of FAS

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe the different ways that FAS was characterized before its actual documentation and classification. (K) ▪ Explain the historical impact of Jones, et al. in the description and identification of FAS in 1973. (K) ▪ Explain the effects of alcohol on the developing embryo and fetus. (K) ▪ Describe characteristics associated with FAS. (K)	▪ Explain the need to understand the basic biomedical foundation of FAS in order to best provide services. (A)	▪ Explain to other health professionals about the basic biomedical foundation of FAS. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal I-B: Explain the basic clinical issues related to FASDs

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Define the basic terminology related to FASDs. (K) ▪ Describe characteristics associated with risk of an alcohol-exposed pregnancy. (K) ▪ Provide an overview of the screening, diagnostic, and assessment processes of FAS. (K)	▪ Recognize characteristics associated with risk of an alcohol-exposed pregnancy. (S) ▪ Recognize characteristics associated with FAS and related conditions. (S)	▪ Explain to other health professionals about the basic clinical issues related to FASDs. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal I-C: Provide an overview of the epidemiological and psycho-social-cultural aspects of FASDs

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Indicate the basic epidemiological data regarding FASDs. (K) ▪ Summarize the economic costs over a lifetime associated with FAS. (K) ▪ Summarize the psycho-social-cultural aspects related to FASDs. (K)	▪ Same as Level 1.	▪ Explain to other health professionals about the epidemiological and psycho-social-cultural aspects of FASDs. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Competency II: Screening and Brief Interventions

The health care student or provider will be able to provide services aimed at preventing alcohol-exposed pregnancies in women of childbearing age through screening and brief interventions for alcohol use.

Learning Goals

(Learning objectives for each goal can be found at the end of this section.)

II-A Screen women of childbearing age for alcohol use at the appropriate time during patient care.

II-B Use demographic and other risk factors appropriately in prevention and screening activities.

II-C Use screening methods, screening tools, and assessment methods appropriately as part of prevention and screening activities.

II-D Conduct brief interventions with women.

II-E Appreciate the use of more extensive interviews to evaluate alcohol consumption during pregnancy.

II-F Define risk drinking and differentiate types of drinkers by patterns of alcohol use.

II-G Assess for referral to treatment.

Content Outline for Competency II

I. Populations needing screening
- A. All women of childbearing age
- B. All pregnant women
- C. High-risk female drinkers
- D. Teens and college-age women
- E. Nursing mothers

II. Risk factors
- A. Demographics
- B. Other risk factors

III. Screening methods
- A. Quantity/frequency, binge, AA score
- B. Screening tools
- C. Screening adolescents and college-age women
- D. Administration of screening tools
- E. Laboratory screening measures

IV. Brief interventions
- A. Background
- B. Brief motivational interviewing
- C. Manualized brief intervention
- D. Computerized brief intervention
- E. Improving clinicians' use of brief intervention
- F. Conclusions regarding the use of brief intervention

V. More extensive interviews used to evaluate alcohol consumption during pregnancy
- A. Health interview for women
- B. NIAAA Health Screening Survey

VI. Definition of risk drinking

VII. Criteria for referral to treatment
- A. Women who are not pregnant
- B. Women who are pregnant

Also included in this section are:

- Suggested learning activities.
- References.
- Chart of all learning goals and objectives for this competency.

I. Populations Needing Screening

Mary J. O'Connor, PhD; R. Louise Floyd, DSN; and Gretchen Guiton, PhD

Alcohol use by women during pregnancy has been associated with negative reproductive, infant, and child health outcomes. Although the most widely recognized consequence of prenatal alcohol exposure is fetal alcohol syndrome (FAS), which occurs in an estimated 2 in 1,000 live births in the United States (May & Gossage, 2001), the literature clearly indicates that FAS is not the only consequence of exposure. Instead, it is suggested that the effects of exposure fall on a continuum now referred to as fetal alcohol spectrum disorders (FASDs) (Streissguth & O'Malley, 2001), which are estimated to occur in 9 or 10 per 1,000 live births (May & Gossage, 2001). Even low levels of alcohol consumption during pregnancy have been associated with negative developmental consequences (Sood et al., 2001). To prevent FASDs, it is important for health professionals to screen and counsel women on their alcohol use.

National Institute on Alcohol Abuse and Alcoholism (NIAAA) Dietary Guidelines for Alcohol Use in Women

According to the NIAAA and the dietary guidelines from the U.S. Department of Health and Human Services, sensible alcohol limits for women include:

- Not drinking more than one standard drink per day.
- Not drinking more than three drinks per drinking occasion.
- Not drinking alcohol at all if you are pregnant, breastfeeding, or planning to become pregnant soon.
- Not drinking alcohol if you are sexually active and not using contraception.
- Not drinking alcohol if you are driving, are taking certain medications, have a history of alcohol or drug dependence, or have certain medical conditions.

A. All Women of Childbearing Age

Alcohol use among women of childbearing age (18 to 44 years) has remained high over the last decade. Recent government surveys indicate that approximately 53% of women report some alcohol use, and approximately 12% report binge drinking, defined as five or more drinks per drinking occasion (Centers for Disease Control and Prevention [CDC], 2002; Substance Abuse and Mental Health Services Administration [SAMSHA], 2004). More recently, the definition of binge drinking for women has been changed to four or more drinks on any one occasion (NIAAA, 2005a). Results further indicate that more than half of women of childbearing age who do not use birth control (and therefore might become pregnant) report alcohol use. Of those women not using effective birth control measures, approximately 13% are sexually active and drink alcohol frequently or binge drink, thereby putting them at high risk for an alcohol-exposed pregnancy (Ebrahim, Anderson, & Floyd, 1999; Tsai & Floyd, 2004). These high levels of general consumption and risk drinking among non-pregnant women of childbearing age are of concern because research has shown that prenatal drinking status is predictive of alcohol use during pregnancy (SAMSHA, 2004). Indeed, many women continue to drink well into the first trimester before they know they are pregnant, which is a particularly vulnerable time for the

developing organ systems of the fetus. Therefore, identifying women who are at high risk for an alcohol-exposed pregnancy and intervening with them before conception is an essential strategy for preventing alcohol-exposed pregnancies.

B. All Pregnant Women

In spite of the robust findings that prenatal drinking is associated with significantly increased negative consequences on fetal growth and child development (Riley & McGee, 2005), data on pregnant women indicate that 10% report drinking alcohol and 2%–4% report binge drinking (Tsai & Floyd, 2004; Wright & Sathe, 2006). Given the updated NIAAA recommendation that a binge episode in women should be considered four or more drinks instead of five or more drinks per occasion (NIAAA, 2005b), current rates are likely much higher than those reported. Indeed, high-risk drinking, thought to increase the risk for infant mortality and morbidity, has not decreased in the last decade, despite significant universal prevention efforts in the form of public service announcements and warning labels on alcohol.

Moreover, in a sample of low-income minority pregnant women participating in the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), the rate of post-conception drinking was 24%, which is much higher than the estimated rate reported previously (O'Connor & Whaley, 2003). Significantly, of the women who reported post-conception drinking, about 62% reported drinking before they knew they were pregnant. As pregnancy recognition in the sample did not occur until after about the 7th week of gestation, many women were drinking well into their first trimester placing their fetuses at significant risk. Therefore, health professionals should be skilled in screening for alcohol use with women from varied cultural backgrounds both during pregnancy and prior to conception.

C. High-Risk Female Drinkers

The probability that an alcohol-dependent woman will have a child with FAS has been estimated to be 25%–45% (Streissguth, 1997). However, along the spectrum of FASDs, it is not uncommon to see an increase in developmental disabilities with each successive pregnancy if the woman continues to drink. The rate of FAS in the offspring of women who have already given birth to a child with FAS has been estimated to be 771 per 1,000 (Abel, 1988), making these women extremely high risk. All women who have previously abused alcohol while pregnant or women who drink and have a child with an FASD should be screened for alcohol consumption.

D. Teens and College-Age Women

1. **Teens.** Alcohol use among adolescents is a serious and growing problem. Forty-six percent of girls in 9th through 12th grade report drinking alcohol, and 28% report binge drinking (described as five or more drinks) (CDC, 2001). Although teen awareness of alcohol's effects on the fetus is particularly important, studies of their beliefs and knowledge about the risks of drinking during pregnancy highlight that a substantial proportion of teens believe that occasional heavy drinking is not harmful, and suggest that teens perceive a safe level of drinking that is higher than the Surgeon General's abstinence recommendations (MacKinnon, Warsi, & Dwyer, 1995).

In one study examining Black or African American, Hispanic, and White, non-Hispanic pregnant adolescents, approximately 22% continued to drink during pregnancy (Rhodes, Gingiss, & Smith, 1994). This percentage is higher than that reported by prevalence studies in the general U.S. population, but it is consistent with reports of drinking during pregnancy in older minority women (O'Connor & Whaley, 2003). Although drinking during pregnancy differs among ethnic groups, in most studies of adolescents, social influences are more relevant than ethnicity in explaining drinking behavior. Thus, it is expected that pregnant teens whose peers use alcohol will be more resistant to reducing their alcohol consumption than will older pregnant women.

2. **College-age women.** Many teens bring established drinking habits with them to college. Several national surveys indicate that more than 80% of college students drink and that about half of those drinkers engage in heavy episodic consumption. More than 40% of college students report recent binge drinking (Wechsler, Davenport, Dowdell, Moeykens, & Castillo, 1994; Wechsler, Dowdall, Maenner, Gledhill-Hoyt, & Lee, 1998; Wechsler, Lee, Kuo, & Lee, 2000). Furthermore, high-risk drinking among female college students is increasing. The Harvard School of Public Heath College Alcohol Study examined nationwide college alcohol use trends in three separate surveys between 1993 and 1999 (Wechsler et al., 1994; 1998; 2000). In these surveys, researchers observed that, in contrast to recent past 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.

   Furthermore, in a time when safe sex practices have been underscored on college campuses, some studies have found that alcohol use might be associated with decreased contraceptive use among youth (Cooper, Peirce, & Huselid, 1994), putting college-age women at risk for unintended pregnancies. One study reported that frequent binge drinkers were 7 to 20 times more likely than nondrinkers to engage in unplanned or unprotected sex (Wechsler et al., 1994), and an estimated 100,000 women per year had sex when they were so intoxicated that they were unable to consent (Hingson, 2002). Because high-risk drinking in college-age women might have the consequence of an unplanned pregnancy, health professionals who work with college women should be skilled in screening them for alcohol use.

E. Nursing Mothers

Studies suggest that infants consume less milk when their mothers consume an alcoholic beverage before nursing than when their mothers consume a nonalcoholic beverage (Mennella & Beauchamp, 1993). Acute exposure to alcohol in mothers' milk has been shown to alter infants' sleep-wake patterns resulting in a reduction in active sleep. A positive association between maternal drinking and delayed infant motor development has also been demonstrated (Lindmark, 1990). In addition to the effects of maternal alcohol consumption on infant nutrition and development, experience with the sensory qualities of alcohol in mother's milk might affect the child's responses to alcohol in the future (Mennella, 2001). For these reasons, it is important for health professionals to discuss alcohol consumption with nursing mothers.

II. Risk Factors

Mary J. O'Connor, PhD; R. Louise Floyd, DSN; and Gretchen Guiton, PhD

Considerable variation in developmental outcome occurs following intrauterine alcohol exposure, and 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.

A. Demographics

When considering risk for alcohol use, the health professional must consider several demographic features of the women with whom they work. These include ethnicity, level of acculturation, socioeconomic status (SES), maternal age, age at first drink, number of children, and marital status.

1. **Ethnicity and acculturation.** Drinking patterns appear to differ among women from different ethnic backgrounds and are influenced by genetic, environmental, historical, and cultural factors (Caetano, 1998; Caetano, Clark, & Tam, 1998). Similar findings have been reported in studies that have concentrated on changes in drinking patterns over time in different ethnic minority populations with special emphasis on women (Caetano, 1994; Helzer & Canino, 1992; Gilbert, 1991). For example, in an analysis of data from the 1988 National Maternal and Infant Health Survey, CDC's National Center for Health Statistics found that 25.4% of White, non-Hispanic women reported drinking during pregnancy compared with 12.2% of Black, non-Hispanic women and 10.6% of Hispanic women (CDC, 1995). However, in a study comparing changes in drinking patterns in a sample of non-pregnant women from 1984 to 1995, the mean rate of consumption for White, non-Hispanic women who were frequent heavy drinkers decreased, whereas the mean for Black and Hispanic women remained the same or increased slightly (Caetano, 1997; Caetano & Clark, 1998). Furthermore, Gilbert (1991) reported an increase in alcohol consumption by Hispanic women with each successive generation following immigration to the United States. Most recently, rates as high as 14.8% have been reported in Hispanic women, suggesting that drinking frequency has increased significantly in this population (Sidhu & Floyd, 2002). The highest rates of drinking during pregnancy in these women were found among those who were younger, more educated, employed, and unmarried. Similarly, higher rates have been reported for Hispanic, English-speaking women compared with Hispanic Spanish-speaking women (O'Connor & Whaley, 2003). Hispanic English-speakers have been shown to exhibit drinking patterns consistent with their White and Black non-Hispanic English-speaking peers. Thus, acculturation appears to interact with other socio-demographic factors in shaping the drinking practices of minority women.

   Asians have typically been considered a "model minority," with high rates of abstention and low rates of heavy alcohol use. This image most likely results from the low numbers of Asian Americans who enter alcohol treatment and from the lack of research on alcohol consumption patterns in this population. Pronounced gender differences also exist: Asian-American women are much more likely than their male counterparts to abstain or consume less of alcohol (Chi, Lubben, & Kitano, 1989). Nevertheless, rates differ among various ethnic subgroups. Drinking rates vary from as high as 67% among Japanese-American

women to as low as 18% among Korean-American women (Chi et al., 1989). Stress and social adjustment have been considered factors contributing to drinking behavior among Asian immigrants. For example, in a study of Cambodian refugee women, 45% acknowledged using alcohol for self-medication for stress and pain (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 been found to report higher levels of alcohol consumption than do less acculturated students (reviewed in Zane & Kim, 1994).

Although prevalence rates for alcohol consumption are highest among American Indians than among other large ethnic groups, alcohol use varies widely among tribes. For example, the Navajo tend to view social drinking as acceptable, whereas the Hopi consider drinking irresponsible (Mail & Johnson, 1993). For this reason, it is wise to know the culture of the tribe from which the woman comes in order to be more informed about her risk for alcohol consumption.

2. **Lower socioeconomic status (SES).** A significant demographic risk factor associated with the drinking behavior of women during pregnancy appears to be socioeconomic status. Despite the fact that drinking prevalence rates are highest among White, non-Hispanic women, as compared with their Black, non-Hispanic and Hispanic counterparts, lower socioeconomic status has been postulated to increase the risk of FAS (Abel, 1995). Abel (1995) reported that, within the United States, the incidence of FAS at sites characterized by low socioeconomic status and Black or American Indian/Alaska Native background were about 10 times higher than at sites with predominant middle or high socioeconomic status and White background. In another study, investigators found that about 40% of 133 Black, non-Hispanic and Hispanic lower-SES infants were diagnosed with FAS, compared with only 3% with FAS among the 109 infants born to a group of White, non-Hispanic upper-middle-class alcoholics in New York (Bingol et al., 1987). Rates were much lower in a standardized multiple-source FAS surveillance study supported by the CDC; however, the incidence of FAS was still highest for Black and American Indian/Alaska Native populations compared with White, non-Hispanic, Hispanic, and Asian/Pacific Islander populations (CDC, 2002). Data from these studies suggest that health professionals must be aware of specific issues that might need to be addressed to successfully work with low-income women in both screening and intervention.

3. **Maternal age.** Maternal age has been shown to be an important moderator of vulnerability to FAS and other alcohol-related deficits, including physical growth, mental development, and information processing speed, with the children of mothers older than 30 years of age showing the most dramatic negative effects (Jacobson & Jacobson, 1996; Jacobson, Jacobson, & Sokol, 1996; Kvigne et al., 2003; O'Connor, Brill, & Sigman, 1986). Nevertheless, epidemiological studies show that younger women have higher rates of heavy drinking and alcohol-related problems than do older women (CDC, 2004; Wilsnack et al., 1994). Women ages 21 to 30 have the highest rates of intoxication, problem drinking, heavy episodic drinking, and alcohol dependency symptoms (Hilton, 1991; Wilsnack & Wilsnack, 1993), and have a low number of abstainers compared with older age groups (Graham, Wilsnack, Dawson, & Wogeltanz, 1998).

4. **Age of first drink.** Data from a national survey of 43,000 adults in the United States suggest that those who began drinking before age 14 are at greater risk of developing alcohol dependence (Hingson, Heeren, & Winter, 2006). Additionally, women who started drinking earlier in life are least likely to stop drinking during pregnancy and are more resistant to intervention (Smith & Coles, 1991; Smith, Lancaster, Moss-Wells, Coles, & Falek, 1987). Smith et al. (1987) reported that among the best predictors of continued drinking during pregnancy was length of drinking history.

5. **Number of children and previous child with FAS.** Studies suggest that the risk for FAS increases with each successive pregnancy. Whereas the risk for FAS is approximately 2 in 1,000 live births in the United States (May & Gossage, 2001), the rate increases to 771 in 1,000 live births for the younger sibling of a child with FAS (Abel, 1988).

6. **Marital status.** Regardless of age, ethnicity, or economic status, women who are separated, divorced, or never married are at greater risk for having a child with FAS or alcohol-related birth defects (NIAAA, 1997).

B. Other Risk Factors

1. **Genetic predisposition.** 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 (for review, 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). Furthermore, in individuals of mixed ancestry in the Western Cape Province of South Africa, the ADH2*2 allele was found to be protective against alcohol-related birth defects in alcohol-exposed offspring and, in studies of Blacks or African Americans, the ADH2*3 allele was associated with fewer alcohol-related birth defects and developmental deficits (Jacobson et al., 2000; McCarver, Thomason, Martier, Sokol, & Li, 1997). 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, as well as 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.

2. **Depression.** An extended analysis of 15 national surveys found that depression contributes to increased drinking levels among women (NIAAA, 1997). In reviews of the literature on women and alcohol use, depression is consistently documented as part of a complex etiology of drinking problems (Gomberg, 1993, 1994). Studies have shown that women who are experiencing symptoms of depression consume more drinks per occasion (Haack, Harford,

& Parker, 1988) and are less able to reduce their alcohol consumption, thus impeding the effectiveness of intervention attempts (Haller, Knisely, Dawson, & Schnoll, 1993; Raskin, 1993). Links between alcohol use and depression have been documented among minority populations, with some studies documenting the strongest associations among African-American women (Grant & Harford, 1995). Studies of Latinas show similar patterns and document an increase in depressive symptoms among low-income Latinas (Caetano, 1987; Golding, Burnam, Benjamin, & Wells, 1993). Furthermore, in a sample of low-income pregnant Latinas, more than 50% of the sample scored in the depressed range on a standardized measure of depression (O'Connor & Whaley, 2006). Depression was also found to play a significant role in continued drinking during pregnancy despite a health care provider's advice to stop. In another study of pregnant women, those who were depressed or who did not have a positive attitude toward the pregnancy were more likely to use alcohol both before and after knowing they were pregnant (Hanna, Faden, & DuFour, 1994). Prevalence rates of depression among pregnant adolescents have been reported to be at least twice as high as among pregnant adults, and these rates have been associated with poor compliance with prenatal care and increased drug and alcohol use (Miller, 1998).

Women who drink alcohol have been shown to have the highest levels of depressive symptoms (Hanna et al., 1994; Meschke, Holl, & Messelt, 2003). Significantly, co-morbid alcohol use and depression have been shown to have negative consequences on infant outcomes. For example, a retrospective report of more than 500,000 women in California found that those diagnosed with co-morbid substance use disorders and psychiatric disorders were more likely to deliver low birth weight and preterm infants than were those with either of these conditions alone (Kelly et al., 2002).

Based on the relationship between depression and alcohol use, it is important to train health practitioners to assess alcohol use in depressed pregnant and non-pregnant women of childbearing age and to be able to recognize depression as a possible risk factor in increased alcohol consumption among women.

3. **Heavy alcohol use in partner and/or family member.** When considering factors that contribute to drinking behavior, of significant importance is the woman's social environment. Women in households in which other family members, especially their spouse, have alcohol problems are more likely to continue to drink during pregnancy (Smith & Coles, 1991; Smith et al., 1987; Wilsnack & Wilsnack, 1993). Both clinical studies and general population surveys have found a positive association between a woman's levels of alcohol consumption and that of her partner (Jacob & Bremer, 1986; Kolonel & Lee, 1981; Wilsnack, Wilsnack, & Hiller-Sturmhofel, 1994). Biological fathers of alcohol-exposed children commonly abuse alcohol, and assortative mating patterns are such that high levels of alcohol abuse are often found in both parents (Abel, 1992; Hall, Hesselbrock, & Stabenau, 1983; Russell, 1990). One study found that women with alcoholic partners were twice as likely to abuse alcohol as women in relationships with nonalcoholic partners (Windle, Windle, Scheidt, & Miller, 1995).

   Family members can influence drinking behavior actively, by explicitly encouraging or discouraging alcohol use, or passively, by providing models of drinking behavior (Graham, Marks, & Hansen, 1991). This is particularly true for adolescent women (Rhodes et al.,

1994). Social influences from friends and family members, particularly mothers, are highly predictive of teen alcohol use (Williams, Epstein, Botvin, Schinke, & Diaz, 1998).

Peers' substance abuse is one of the strongest predictors of alcohol use during pregnancy (Lohr, Gillmore, Gilchrist, & Butler, 1992), as is family alcohol use (Rhodes et al., 1994). The potential impact of social support on prenatal alcohol use was found to be particularly important in a study in which subjects identified social events, specific celebratory occasions, family history of alcohol problems, and partner's use of alcohol as risk factors for prenatal alcohol consumption (Chang, Goetz, Wilkins-Haug, & Berman, 2000). Thus, it is likely that women of all ages whose social environments encourage alcohol use will be less amenable to reducing their drinking during pregnancy. For these reasons, it is important for health practitioners to consider alcohol abuse in a partner or family member as a risk factor when screening women.

4. **Binge drinking pattern.** Heavy episodic drinking has been identified as an important risk factor because of the demonstrated association between binge drinking and unintended pregnancy (Foster, Vaughan, Foster, & Califano, 2003; Naimi, Lipscomb, Brewer, & Gilbert, 2003) and between higher peak blood alcohol levels and increased magnitude of the teratogenic effects of alcohol on the fetus (Avaria, Mills, & Kleinsteuber, 2004). Several factors might explain why binge drinking is harmful to fetal brain development (Maier & West, 2001). First, the peak blood alcohol concentrations (BACs) achieved with this drinking pattern are higher than the peak BACs achieved with lower quantity, continuous drinking patterns. Another consequence of higher peak BACs is prolonged alcohol exposure for the pregnant woman, which produces longer periods of alcohol exposure for the developing fetal brain than does consumption and metabolism of a single drink. High and prolonged BACs are critical factors in producing fetal brain injury by potentiating apoptosis during synaptogenesis. The timing of binge drinking episodes relative to key stages of fetal development might influence the extent of adverse effects. Some sensitive developmental periods are of short duration; a single binge episode that occurs during one or more of these periods could produce profound adverse effects. Alcohol consumption in a binge pattern also exposes the developing fetal brain to periods of withdrawal from alcohol, which might be a risk factor for developmental brain injury.

5. **Use of other substances, cigarette smoking; abuse and multiple sex partners; sexually active women.** Results of a recent study of 2,672 English-speaking women aged 18 to 44 from six different outpatient treatment settings and an urban jail revealed that recent drug use, history of smoking more than 100 cigarettes, and history of inpatient treatment for drugs, alcohol, or mental health treatment correlated significantly with risk for an alcohol-exposed pregnancy (Project CHOICES Research Group, 2002). Having multiple sex partners and recent physical abuse were also related to risk.

6. **Alcohol expectancy in adolescence.** Alcohol expectancies—positive or negative beliefs about the consequences of using alcohol—constitute a powerful construct for examining cognitions about alcohol because they might play a causal role in the initiation and maintenance of alcohol use. Some studies have accounted for 50% or more of the drinking variance attributed to alcohol expectancies when sophisticated instruments and analytic techniques were employed (e.g., Goldman, Greenbaum, & Darkes, 1997)

With regard to young women, Brown (1985) demonstrated that alcohol expectancies yielded better predictive capacity for college drinking than did demographic variables. Furthermore, college students' expectancies were differentially related to problematic and non-problematic patterns of college drinking. Social drinkers were shown to expect social enhancement from alcohol, whereas problem drinkers were more likely to expect tension reduction from alcohol. Other studies using college samples have demonstrated that heavier drinkers report more positive effects over all dimensions than do lighter drinkers (Bogart, Yeatman, Sirridge, & Geer, 1995; Leigh & Stacy, 1991).

7. **High-risk drinking.** In a recent study conducted at UCLA on low-income minority women, after numerous demographic measures were considered, the best predictor of alcohol use was the woman's score on a screening measure of high-risk drinking (O'Connor & Whaley, 2003, 2006).

Although these risk factors that have been identified as important to consider when thinking about possible alcohol use in women, they should not be used to establish a profile of a typical drinker or to eliminate possible women from universal screening. Nevertheless, health care professionals should be aware of these risk factors when working with women of childbearing age.

III. Screening Methods

Mary J. O'Connor, PhD; R. Louise Floyd, DSN; and Gretchen Guiton, PhD

Primary care physicians need to ask all women they see about alcohol use. One of the main challenges to identifying a group of at-risk alcohol users, particularly in a nonmedical sample, is to effectively screen for alcohol use and related problems using reliable methods (Midanik, Zahnd, & Klein, 1998). Despite substantial literature on the validity and reliability of self-report of alcohol use and abuse (reviewed in Babor, Brown, & Del Boca, 1990; Maisto, McKay, & Connors, 1990; Sobell & Sobell, 1990), the issue of underreporting of drinking levels must always be considered. Factors shown to increase accurate and truthful reporting include (a) being certain the individual is alcohol-free when interviewed, (b) ensuring confidentiality, (c) conducting the interview in a clinic setting, and (d) wording questions and questionnaires clearly (Brown, Kranzler, & Del Boca, 1992; Sobell & Sobell, 1990). Furthermore, using more than one alcohol consumption measure can enhance the validity of self-report (Day & Robles, 1989). When screening women in a busy clinic setting, it is important that the screening instrument be easy to administer and relatively brief.

Each screening instrument has particular strengths and weaknesses and varies in its applicability to clinical settings. When selecting a screening tool for routine implementation, health care professionals should consider factors such as the goals of the screening process, features of the target population (age, pregnancy, ethnicity, literacy rates, etc.), and the ease of administration.

A. Quantity/Frequency, Binge, AA Score

The physicians' guide developed by NIAAA (1999) recommends quantity/frequency and binge-drinking questions as the primary screening test. Although denial can be triggered by direct questioning about alcohol consumption patterns, particularly in heavy consumers, when asked in a standardized nonjudgmental manner, with the questions embedded in the context of a general medical history screen, relatively high sensitivity and specificity can be achieved with minimal cost and effort (NIAAA, 2003).

Quantity-frequency measures (QF) 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 investigators have recommended that screening questions should include measures of maximum quantity consumption and include frequency of maximum quantity (QVF) (Day & Robles, 1989). QF measures can be used to estimate a woman's average amount of alcohol consumed per day (AA score). Using QF measures, non-pregnant women who consume more than seven drinks per week or who have binge episodes of more than three drinks are considered high risk (NIAAA, 2005a). Pregnant women are advised that there is no safe amount of alcohol during pregnancy.

An additional feature that should be included in any QF assessment is the measurement of the types of alcoholic beverages most often consumed. It has been traditional in alcohol research to assume that all drinks are equivalent in terms of the amount of absolute alcohol. That is, a standard drink is defined as 0.60 ounces of pure alcohol, which is equivalent to one 12-ounce beer or wine cooler, one 5-ounce glass of wine, or 1.50 ounces of 80-proof distilled spirits (Table 2.1).

Table 2.1. How to Compute a Standard Drink

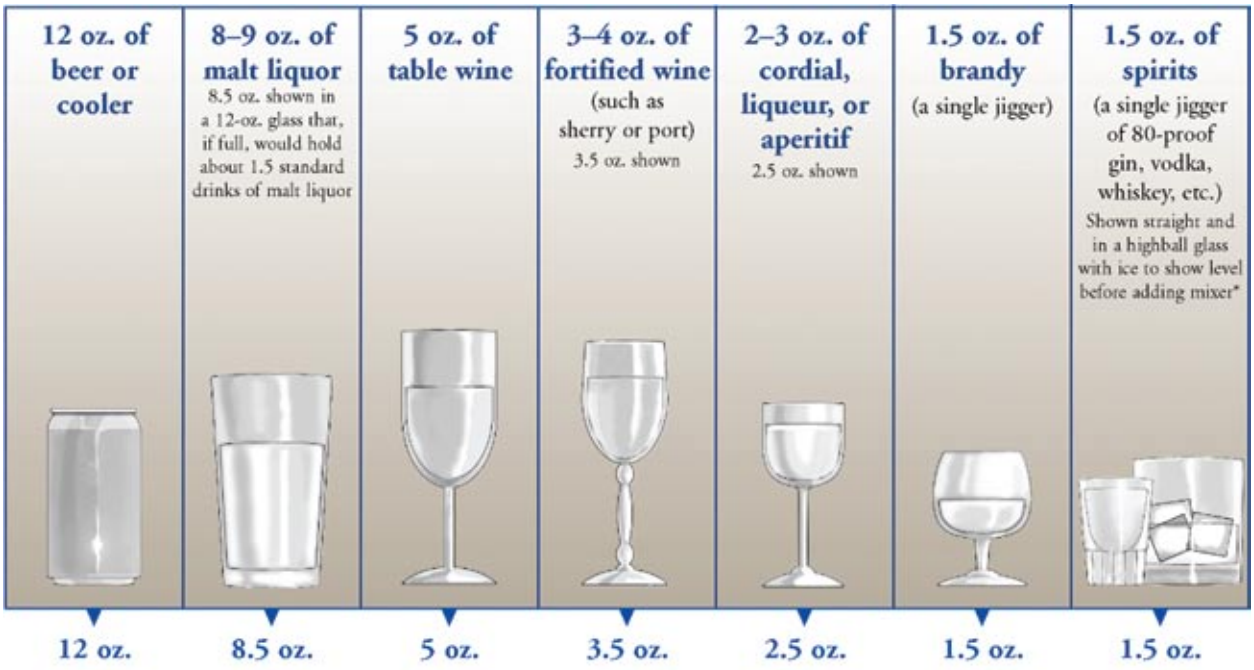
A standard drink (SD) is considered to be 0.60 ounces of absolute alcohol (aa).

- One 12-ounce can of beer containing 5% aa (12 x 0.05 = 0.60 = 1 SD)
- One 5-ounce glass of wine containing 12% aa (5 x 0.12 = 0.60 = 1 SD)
- One 4-ounce glass of fortified wine containing 15% aa (4 x 0.15 = 0.60 = 1 SD)
- 1.5 ounces hard liquor or spirits containing 40% aa (1.50 x 0.40 = 0.60 = 1 SD)
- One 12-ounce bottle of wine cooler containing 5% aa (12 x 0.05 = 0.60 = 1 SD)
- One 16-ounce can of malt liquor containing 8% aa (16 x 0.08 = 1.20/0.60 = 2 SD)
- One 40-ounce bottle of malt liquor containing 8% aa (40 x 0.08 = 3.20/0.60 = 5.33 SD)
- One Colt 45-ounce bottle of beer containing 6% aa (45 x 0.06 = 2.70/0.60 = 4.50 SD)
- One Margarita bar drink (1.5 x 0.40 = 0.60 = 1 SD)
- One Long Island Ice Tea bar drink (2.25 x 0.40 = 0.90/0.60 = 1.5 SD)

Source: O'Connor & Whaley, 2007, UCLA Project Care, NIAAA grant #AA12480

However, the development of new ways of marketing wine and beer, including high-alcohol-content malt liquors and beer in 22- to 45-ounce containers, has increased the need to provide women who drink with more specific standards by which to compare their drinking. Furthermore, studies show that when asking heavier drinkers and those consuming high-alcohol-content beverages about their consumption, reliance on standard drinks results in considerable underestimation. For this reason, before screening, women should first be taught what constitutes a typical drink and be provided with vessel size estimates in the form of physical props (Figure 2.1; Hankin & Sokol, 1995; Kaskutas & Graves, 2001). Moreover, beverage-specific questions have been shown to be more accurate than grouped beverage questions; ask about beer, wine, wine coolers, cocktails, or liqueur separately (Serdula, Mokad, Byers, & Siegel, 1999). The American College of Obstetricians and Gynecologists (ACOG, 2006) has provided a physician's guide illustrating standard-sized drinks for a number of beverages in a recent publication entitled, *Drinking and Reproductive Health: A Fetal Alcohol Spectrum Disorders Prevention Tool Kit*. This tool kit can be ordered online from ACOG: http://www.acog.org/.

Figure 2.1. Alcohol Equivalents



Source: National Institute on Alcohol Abuse and Alcoholism. (2005a). *Helping patients who drink too much: A clinician's guide, Updated 2005 Edition*. NIH Pub. No. 07-3769. Bethesda, MD: U.S. Department of Health and Human Services.

*It can be difficult to estimate the number of standard drinks in a single mixed drink made with hard liquor. Depending on factors such as the type of spirits and the recipe, a mixed drink can contain from one to three or more standard drinks.

B. Screening Tools

1. **T-ACE and TWEAK.** Several short questionnaires currently exist that have been used to screen for problematic alcohol use and have been evaluated in multiple settings. These include the MAST, the S-MAST, the T-ACE, the TWEAK, the NET, the AUDIT, the AUDIT-C, the RAPS4, the RAPS4-QF, and the CAGE (Chan, Pristach, Welte, & Russell, 1993; Cherpitel, 2002; Dawson, Grant, Stinson, & Zhou, 2005; Ewing, 1984; Midanik et al., 1998; Rosett, Weiner, & Edelin, 1981; Russell, 1994; Russell et al., 1996). In general, a positive screen does not indicate an alcoholism diagnosis, but rather a need to discuss pregnancy risk drinking.

   Of these screening tools, the two used most commonly with pregnant women are the T-ACE and the TWEAK. The T-ACE has four questions that take less than a minute to ask. The questions are:

   T TOLERANCE. How many drinks does it take to make you feel high?
   A Have people ANNOYED you by criticizing your drinking?
   C Have you ever felt you ought to CUT DOWN on your drinking?
   E EYE OPENER. Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover?

   One point is given for each affirmative answer to the A, C, E questions, and 2 points are given when a pregnant woman reports a tolerance of three or more drinks to feel high. A positive screen is a score of 2 or more points.

   Like the T-ACE, the TWEAK attempts to elicit the following:

   T TOLERANCE for alcohol.
   W WORRY or concern by family or friends about drinking behavior.
   E EYE OPENER, the need to have a drink in the morning.
   A "Blackouts" or AMNESIA while drinking.
   K The self-perception of the need to CUT DOWN on alcohol use.

   Scores range from 0 to 7. The tolerance and worry questions each contribute 2 points and the other three questions contribute 1 point each. Any endorsement of the worry question is scored a 2. On the tolerance question, if three or more drinks are needed to feel the effects of alcohol, the question is scored as a 2. (Other versions of the tolerance question ask: How many drinks does it take before the alcohol makes you fall asleep or pass out? Or, if you never drink till you pass out, what is the largest number of drinks you have or can hold? These questions are scored as a 2 if the woman answers five or more drinks. Using these questions, however, results in lower sensitivity and specificity). A total score of 3 or more on the TWEAK is suggestive of harmful drinking (Chan et al., 1993). The sensitivity of the TWEAK for predicting current alcohol consumption in pregnant women can be increased using a cut point of 2 or more (Russell et al., 1994). For screening purposes, increased sensitivity is desirable.

   Bradley, Boyd-Wickizer, Powell, and Geer (1998) analyzed 13 published, peer-reviewed articles and concluded that the five-item TWEAK appears to be the optimal screening questionnaire for identifying alcohol use in women. The TWEAK proved most sensitive across ethnic

groups and has been suggested for additional use with pregnant women not only because of its promising performance to date, but also because it was designed for use in obstetric/gynecologic clinics and other primary health care settings.

2. **AUDIT-C.** A large epidemiological study examined the use of the AUDIT-C on a sample derived from the 2001–2002 National Epidemiologic Survey on Alcohol and Related Conditions (NESARC) conducted by the NIAAA (Dawson et al., 2005). The NESARC AUDIT-C included modifications to the first three questions of the original AUDIT (Saunders et al., 1993) and was based solely on items reflecting alcohol consumption. The tool was developed to match the brevity and ease of administration provided by other brief screening instruments. The three questions on the screen are:

   - During the last 12 months, about how often did you drink ANY alcoholic beverage?
   - Counting all types of alcohol combined, how many drinks did you USUALLY have on days when you drank during the last 12 months?
   - During the last 12 months, about how often did you drink FIVE OR MORE drinks in a single day?

   Scores range from 0 to 4 on each question. The AUDIT-C demonstrates good sensitivity and specificity at a cut point of 3 or greater for identifying risk drinking in non-pregnant and pregnant women, and it performs well across different racial and ethnic groups.

3. **Timeline Follow Back.** Not surprisingly, more intensive interview methods have been shown to be effective means of determining alcohol use. The Timeline Follow Back (TLFB) method, for example, provides a detailed picture of a person's drinking over a designated time period (Sobell & Sobell, 1995). It has been evaluated extensively with clinical and nonclinical drinker populations (Sobell & Sobell, 1992) and yields data on the pattern, variability, and level of drinking. Hankin and Sokol (1995), for example, successfully used TLFB interview techniques to determine the amount of alcohol consumed by pregnant women around the time of conception and the amount consumed in the 2 weeks prior to their prenatal visit. Although this method might be highly effective for a more in-depth evaluation of a woman's drinking pattern, it might not be appropriate for screening purposes in busy clinics or among large samples of women. Nevertheless, an abbreviated TLFB method inquiring about very recent alcohol use and use during the previous weekend might increase feasibility of use.

4. **Trauma Questionnaire.** A number of studies have shown a strong association between alcohol intoxication and trauma (Howland & Hingson, 1987). The Trauma Questionnaire was developed to screen patients in an unobtrusive way without asking them directly about their alcohol use (Israel et al., 1996). The questionnaire consists of four questions asking about injuries in the last 5 years (fractures or dislocations of bones or joints, traffic accidents, head injury, or injury during a fight or assault). The questionnaire has been shown to have high sensitivity and specificity for identifying high-risk alcohol use and to be acceptable to respondents and physicians.

5. **UCLA Alcohol Screener.** The previously mentioned techniques have also been used successfully to screen pregnant drinkers in a California sample of low-income, minority women participating in WIC (Whaley & O'Connor, 2003). On the self-report screener,

women were asked how much they drank on an average day (Q) and the average number of days on which alcohol was consumed (F). These questions were asked for the period after conception but before pregnancy recognition, and for current drinking (after pregnancy recognition). Women were also asked how many times they had consumed three or more drinks in a single episode and whether or not they had any alcohol during the previous weekend, week, or month. The TWEAK was included in the screener to assess high-risk drinking. Women were considered to screen positive for alcohol consumption during pregnancy if they reported any alcohol consumption since conception on any of the measures. Using this screening method, 15% of women who drank after they knew they were pregnant were identified compared with 5% using the WIC standard of care of simply asking if women if they drank any alcohol in the last month (Whaley & O'Connor, 2003). All women who screened positive for any alcohol use were then given a brief intervention. This tool has not yet been validated against other screening measures for identifying high-risk women, but it might be promising for screening in a busy outpatient clinic while women are waiting to see their health care provider.

C. Screening Adolescents and College-Age Women

The use of screening tools developed for adults is not recommended for screening adolescents and college-age youths. Rather, measures such as the Rutgers Alcohol Problem Index (White & Labouvie, 1989) and the College Alcohol Problem Scale (O'Hare, 1997) should be considered. One brief screening device, the CRAFFT, was developed for adolescents. It is simple to score, asks about alcohol and drug use, and has good psychometric properties in a sample of predominately female youths between the ages of 14 and 18 (Knight, Shrier, & Bravender, 1999).

CRAFFT asks the following six questions:

- **C** Have you ever ridden in a CAR driven by someone (including yourself) who was high or had been using alcohol or drugs?
- **R** Do you ever use alcohol or drugs to RELAX, feel better about yourself, or fit in?
- **A** Do you ever use alcohol or drugs while you are by yourself, ALONE?
- **F** Do you ever FORGET things you did while using alcohol or drugs?
- **F** Do your family or FRIENDS ever tell you that you should cut down on your drinking or drug use?
- **T** Have you ever gotten into TROUBLE while you were using alcohol or drugs?

Each question on the CRAFFT is given a score of 1, and a cut point of 2 provides moderate sensitivity (0.70) and excellent specificity (0.94) for identifying alcohol use disorders in adolescents. The authors recommend that any positive answer on the CRAFFT be followed by further assessment of quantity, frequency, and pattern of use to increase sensitivity and to guide decisions about the need for intervention.

D. Administration of Screening Tools

1. **Self-report versus face-to-face interview.** The method of delivery of questions about alcohol use has been shown to influence truthful reporting. Clinical interviews might not be as effective in eliciting truthful responses from women because practitioners are not always

comfortable asking these questions in a face-to-face interview. Moreover, women might underestimate alcohol use because of reluctance to discuss this potentially sensitive subject. For this reason, self-administered questionnaires might improve the validity of self-report.

2. **Computer-assisted interviews.** The Audio Computer-Assisted Self-Interviewing (ACASI) technology has been used successfully in prenatal clinics serving disadvantaged, low-literate, minority women (Thornberry et al., 2002). Questions drawn from the TWEAK and quantity/frequency questions pertaining to 3 months before and during pregnancy are asked by a recorded voice through earphones. Patients can answer questions by pressing a few keys on the computer. Advantages include ease of use for respondents with poor literacy or computer skills, as well as increased privacy (Lessler, Caspar, Penne, & Barker, 2000). Acceptability studies revealed that patients liked this method of screening.

E. Laboratory Screening Measures

Laboratory screening measures offer promise for obtaining objective evidence of problem drinking (Allen, Litten, Fertig, & Sillanaukee, 2000; Bearer, 2001). The most common biomarkers are GGT (gamma glutamyltransferase) and CDT (carbohydrate-deficient transferrin). Fatty acid ethyl esters synthase (FAEE) can be found in the hair of women who use alcohol. This biomarker might hold promise for screening for alcohol use in pregnant women, although the dynamics of enzyme expression appear to be complex, and changes occur only at high alcohol doses. Low sensitivity in non-alcoholic women and the high cost of laboratory analysis make these measures less feasible for use in more universal screening.

IV. Brief Interventions

Mary J. O'Connor, PhD; R. Louise Floyd, DSN; and Gretchen Guiton, PhD

A. Background

Brief intervention (BI) has been shown to be an effective, low-cost treatment alternative for alcohol problems that uses time-limited, self-help, and preventative strategies to promote reductions in alcohol use in nondependent individuals, and in the case of dependent persons, to facilitate their referral to specialized treatment programs (Bien, Miller, & Tonigan, 1993; Fleming, 2003). Overall, BI for alcohol problems has been shown to be more effective than no intervention and often is as effective as more extensive intervention. Effective prevention programs frequently employ a multicomponent approach combining cognitive-behavioral skills with norms clarification, education, and motivational enhancement. BI is usually restricted to fewer than four sessions and is typically performed in a treatment setting that is not specific for alcoholism. It is often performed by personnel who are not specialized in the treatment of alcohol use and abuse and is provided to individuals at varying risk for negative consequences caused by drinking, rather than to those who are considered alcohol dependent (NIAAA, 1997). In 2004, the U.S. Preventive Services Task Force reported evidence-based recommendations citing screening and brief intervention as the standard of care for intervening in alcohol use problems in adults and extended the recommendation to pregnant women as well.

1. **Components of Brief Intervention.** Six elements characterize the key ingredients of standardized brief intervention, summarized by the acronym 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.

    The intervention also involves establishing a drinking goal in the form of a signed contract and follow-up of progress with ongoing support. See Table 2.2 for an example of a brief intervention for a pregnant woman.

Table 2.2. 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. Did you know that there is no safe amount of drinking when you are pregnant because alcohol exposure can hurt a developing baby? No one can make you decide to change your drinking. What you do about your drinking is up to you. But you can have a healthier baby if you stop drinking now. A baby who has been exposed to alcohol during pregnancy might have some problems."

> MAJOR PROBLEMS: small size, mental retardation, facial deformities, heart problems
>
> OTHER PROBLEMS: eating and sleeping problems, hyperactivity and inattention, language delays, memory and learning, hearing and vision, social problems, motor delays

ADVICE TO CHANGE
"The best advice for a pregnant woman is to not drink any alcohol."
Ask for a response to your advice to make sure the patient understands the need to take action: "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 some 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 5, how sure are you that you can stop (lower) your drinking? 1 means you think you CANNOT stop (cut down) your drinking, and 5 means you are sure you CAN stop (cut down) your drinking."

"If you feel that you cannot stop drinking right now, here are ways to cut down.

- 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.
- Do not drink three or more drinks per drinking occasion."

ENCOURAGEMENT AND FOLLOW-UP
"Changing your behavior can be hard. It will get easier.

- 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: O'Connor & Whaley, 2007, UCLA Project Care, NIAAA grant #AA12480

2. **Characteristics of interviewer and interview techniques.** Studies reveal that supportive, nonjudgmental techniques in which trained personnel counsel women lead to decreased alcohol consumption during pregnancy. The most effective intervention approaches avoid the use of moral or volitional injunctions and instead focus on reduction of alcohol use without criticism or provocation of guilt (NIAAA, 1997). Effective interviewers 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).

B. Brief Motivational Interviewing

Motivational interviewing (MI), one form of BI, is an empathic, patient-centered counseling approach for increasing readiness for change by resolving ambivalence about behavior change (Miller & Rollnick, 1991). The process involves exploring the client's ambivalence in an atmosphere of acceptance, warmth, and positive regard. Although the session is directive, direct persuasion and coercion are avoided. The goal is to enhance the discrepancy between the reasons for changing versus the reasons for staying the same. More than 24 studies of motivational interviewing have yielded beneficial effects in decreasing problem drinking and other health-related problem behaviors (Miller, 2000).

CDC-funded Project CHOICES (Changing High-risk alcOhol use and Increasing Contraception Effectiveness Study) is an example of a selective intervention using motivational interviewing aimed at preventing alcohol-exposed pregnancies among high-risk women in special community settings (Project CHOICES Research Group, 2003). This project focused on providing women two alternatives: reducing risk drinking levels or instituting effective contraception. Participants were non-pregnant women who were of childbearing age, fertile, sexually active, and using ineffective or no contraception at study commencement. The intervention consisted of four sessions using motivational interviewing and one contraceptive counseling session aimed at moving the women to change one or both of the target behaviors. Results revealed that at 6-month follow-up, 68.5% of women had lowered their risk of having an alcohol-exposed pregnancy: 13%reduced their drinking only; 23.1% reported using effective contraception only; and 32.9% reported doing both (Project CHOICES Research Group, 2003).

Like Project CHOICES, another CDC-funded study was aimed at female college students who were sexually active, using ineffective birth control, and drinking at high-risk levels. In a one-session motivational interview, they were encouraged to abstain from alcohol or to use contraception if they drank. At 1-month follow-up, 74% of women in the brief intervention group were no longer at risk compared with 54% of women in the control group (Ingersoll et al., 2005).

C. Manualized Brief Intervention

Although the findings of the studies discussed previously provide the foundation for intervention and prevention efforts, the usefulness of MI in a busy clinic or medical practice might be limited because it requires considerable training and clinical skill. Standardized, manualized BI techniques to reduce alcohol consumption have been developed. Four randomized controlled studies, funded by NIAAA, serve as examples of the effectiveness of this approach. These studies included women of different socioeconomic and cultural backgrounds and were conducted in doctors' offices and community settings. Two studies found that manualized BI was successful in decreasing alcohol use during subsequent pregnancies in high-risk women, thus preventing possible negative developmental sequelae in their offspring (Hankin, Sokol, Casentrelli, & Shernorr, 2000; Manwell, Fleming, Mundt, Stauffacher, & Barry, 2000). Two other studies, one working with high-risk, white, middle-class pregnant women in physicians' offices, and one working in WIC community clinics with primarily low-risk, low-income Hispanic clients, also found manualized BI to be a promising approach (Chang, Wilkins-Haug, Berman, & Goetz, 1999; Chang et al., 2000; 2005; O'Connor & Whaley, 2007). Significantly, these two studies found that the control conditions, which included an assessment of alcohol consumption and simple advice to stop or cut down on drinking, were almost as effective in helping women reduce their drinking levels as was the manualized BI itself. The success of these projects in reducing alcohol consumption in both experimental and control groups was postulated to be due to the desire of pregnant women to have healthy pregnancies and to the time and attention that interventionists provided to women in both groups. Even so, BI was found to be most effective with women who were drinking at higher levels (Chang et al., 2005), and better infant outcomes, including higher birth weights, longer birth lengths, and lower mortality rates, were reported for newborns of heavier drinkers who were provided with BI (O'Connor & Whaley, 2007). Results of these studies provide evidence of the efficacy of standardized brief intervention strategies with pregnant women for promoting reductions in alcohol consumption.

D. Computerized Brief Intervention

A potential tool for administering an 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, and it is easily used even by those with little computer experience. This approach has yet to be tested on pregnant women.

E. Improving Clinicians' Use of Brief Intervention

Research devoted to finding ways to encourage wider use of brief interventions by clinicians indicates that current routine educational approaches might not be effective. Strategies found to be effective included (a) conducting educational programs at the intervention site; (b) using specific step-by-step, evidence-based clinical protocols; (c) using skills-based role playing; (d) holding peer group discussions; and (e) using a credible expert trainer or educator. Brevity, repetition, and reinforcement of recommended practices are also key program elements (Brown & Fleming, 1998). Importantly, as of January 2007, new billing codes are available through the Medicaid program for physician reimbursement for alcohol screening and brief intervention.

F. Conclusions Regarding the Use of Brief Intervention

Research to date suggests that routine, formal screening for alcohol use should be conducted with all women of childbearing age. Screening can be done in both physicians' offices and in community health settings. Simple screening tools have been found to be beneficial for both non-pregnant and pregnant women. The T-ACE and the TWEAK, in particular, are recommended for pregnant women. The CRAFFT shows promise as a screener for alcohol and other drugs among female adolescents. Simple screening questions that include measures of quantity and frequency and heavy episodic drinking, such as those used on the AUDIT-C, have proven beneficial.

BI administered by physicians and allied health professionals in medical and non-medical settings are effective in bringing about reductions in drinking in the preconception and pregnancy periods. Women who are pregnant, planning a pregnancy, or at risk for pregnancy should be advised not to drink, as damage to the fetus can occur before they know they are pregnant, and no safe threshold of alcohol use during pregnancy has been established. Women who are fertile, sexually active, and not using effective contraception should be advised that they are at risk for an alcohol-exposed pregnancy and should abstain from alcohol use or establish effective contraception. Women of childbearing age who are using effective contraception should be advised to drink no more than seven drinks per week and no more than three drinks on any one occasion.

Recent surveys of practicing obstetricians-gynecologists support the need and desire for information on effective means of screening and counseling women who report alcohol use (Diekman et al., 2000). To enhance physician use of current screening and intervention approaches for preventing alcohol-exposed pregnancies, federal agencies have developed and disseminated clinical guidelines and tools for primary care professionals for screening pregnant and non-pregnant women on alcohol use and recommendations for appropriate advice depending on the level of alcohol use and consequences. Additionally, in 2002, CDC funded four regional training centers to provide education and training to medical and allied health professionals and students in identifying and diagnosing children affected by prenatal alcohol exposure and in effectively intervening with and preventing these conditions. Finally, the American College of Obstetricians and Gynecologists, under the auspices of CDC, has developed materials to enhance formal screening and BI provided by physicians and nurse practitioners.

V. More Extensive Interviews Used To Evaluate Alcohol Consumption During Pregnancy

Mary J. O'Connor, PhD; R. Louise Floyd, DSN; and Gretchen Guiton, PhD

A. Health Interview for Women

The Health Interview for Women is an adaptation of an interview developed by Day and Robles (1989) that requires the pregnant woman to estimate the extent of her current alcohol use (O'Connor, 2003). This interview was used in the UCLA WIC study to decrease drinking levels in low-income, pregnant, minority women. It inquires about the woman's drinking before pregnancy recognition and about current use—now that the woman knows that she is pregnant. The Health Interview yields standard alcohol measures of average number of drinks per drinking occasion, maximum drinks per occasion, and the frequency of both. The brand of alcohol the woman uses and the estimated number of ounces consumed is included. Questions about other teratogen use, including smoking, caffeine, and prescription and illegal drug use, are also included on the interview and are quantified using methods developed by Jacobson et al. (1994). Table 2.3 shows the Health Interview for Women used in the UCLA WIC study.

Table 2.3. UCLA Health Interview for Women

This questionnaire is designed to survey your health-related habits.

How many weeks pregnant were you when you FIRST found out that you were pregnant? ___ WEEKS

Before you knew you were pregnant:

1. How many servings a day did you have of:

   a. Coffee (caffeinated)..... ___ CUPS

   b. Tea (non-herbal) ..... ___ CUPS

   c. Cola drinks with caffeine ..... ___ DRINKS

2. How many cigarettes did you smoke on a typical day? ___ # OF CIGARETTES

3. On days that you drank alcohol, how many drinks did you usually have of…?

4. How often did you drink this amount of (beer/liquor/ wine)? IF THE WOMAN DENIES DRINKING, PUT ZEROS IN THE DRINKS COLUMN. OTHERWISE CIRCLE ONE OF THE FOLLOWING.

	DRINKS	Daily	Almost every day	3-4 days a week	1-2 days a week	2-3 days a month	Once a month	Less than once a month
a. Beer	___	7	6	5	4	3	2	1
b. Liquor	___	7	6	5	4	3	2	1
c. Wine.....	___	7	6	5	4	3	2	1

5. Did you have days when you drank more (beer/ liquor/wine) than usual? If so, how much?

6. How often did you drink this amount of (beer/liquor/ wine)? IF THE WOMAN DENIES DRINKING, PUT ZEROS IN THE DRINKS COLUMN. OTHERWISE CIRCLE ONE OF THE FOLLOWING.

	DRINKS	Daily	Almost every day	3-4 days a week	1-2 days a week	2-3 days a month	Once a month	Less than once a month
a. Beer	___	7	6	5	4	3	2	1
b. Liquor	___	7	6	5	4	3	2	1
c. Wine.....	___	7	6	5	4	3	2	1

7. How many drinks did it take until you felt the effects of alcohol? **Circle only one.**

21	20	19	18	17	16	15
14	13	12	11	10	9	8
7	6	5	4	3	2	1

8. Did close friends or relatives worry or complain about your drinking? **Check only one.**
   - ☐ Yes
   - ☐ No

9. Did you sometimes take a drink in the morning when you first got up? **Check only one.**
   - ☐ Yes
   - ☐ No

10. Did a friend or family member ever tell you about things you said or did while you were drinking that you could not remember? **Check only one.**
    - ☐ Yes
    - ☐ No

11. Did you sometimes feel the need to cut down on your drinking? **Check only one.**
    - ☐ Yes
    - ☐ No

12. Did you smoke marijuana? **Check only one.**
    - ☐ Yes
    - ☐ No

13. How many joints did you smoke on a typical day? (1 BLUNT = 5 JOINTS)

    ☐☐
    # OF JOINTS

14. On average, how often did you smoke marijuana? **Check only one.**
    - ☐ Daily
    - ☐ Almost every day
    - ☐ 3-4 days a week
    - ☐ 1-2 days a week
    - ☐ 2-3 days a month
    - ☐ Once a month
    - ☐ Less than once a month
    - ☐ Never

15. **D**id you take any of the following? **Check only one.**

	None	1–2 times per week	3 or more times per week
a. Aspirin/Tylenol/ibuprofen	❑	❑	❑
b. Antibiotics	❑	❑	❑
c. Tranquilizers	❑	❑	❑
d. Pain pills (Dilaudid, dillies, morphine, Vicodin).....	❑	❑	❑
e. Barbiturates (barbs, downers, reds, Seconal, sedatives, sleeping pills)	❑	❑	❑
f. Amphetamine (Ritalin, pellets, uppers, crank, crystal, meth, bennies, blancas, speed, glass, ice)	❑	❑	❑
g. Cocaine (coke, snow, blow, crack, rock, eightball, freebase).....	❑	❑	❑

15.	**D**id you take any of the following? **Check only one.**	None	1–2 times per week	3 or more times per week
	h. Methadone/heroin.....	❑	❑	❑
	i. Hallucinogens (acid, LSD, magic mushrooms, shrooms, microdots, micro tabs, lucy, dip, ecstacy, X, MDMA, hog, mescaline, peyote, windowpane, PCP, angel dust).....	❑	❑	❑
	j. Non-medical inhalants.....	❑	❑	❑
	k. Medications for seizures or epilepsy (Dilantin, Tegretol, Traxine, Depakene, valproic acid).....	❑	❑	❑
	l. Antidepressants (Prozac, Luvox, Effexor, Paxil, Zoloft, Elavil, Pamelor, Wellbutrin).....	❑	❑	❑

Now consider your health habits now that you know you are pregnant.

Questions 1 through 15 are repeated reminding the woman that you are now asking her about behavior after pregnancy recognition.

Source: O'Connor & Whaley, 2003, NIAAA grant #AA12480
Adapted from: Day N. L ., & Robles, N. (1989). Methodological issues in the measurement of substance abuse. *NYAS 562*, 8-13.

B. NIAAA Health Screening Survey

The NIAAA health screening survey (1999) is composed of two sets of questionnaires, one for women of childbearing age who are not pregnant, and one for women who are pregnant. Using a decision tree format, the screener starts with general health-related questions, then asks about drinking in the last 3 months and includes the T and W questions from the TWEAK. If a woman screens positively on any of the alcohol related questions, she is then asked nine questions about negative consequences associated with her drinking. Based on her responses, she is classified as an at-risk drinker, problem drinker, or possibly alcohol-dependent. The screener for pregnant women uses the same questions as those for non-pregnant women, but the respondent is asked about drinking 3 months prior to pregnancy and currently, during pregnancy. The tolerance for classifying risk is lower for pregnant women than for non-pregnant women. Table 2.4 shows the NIAAA Health Screening Questions.

Table 2.4. NIAAA Health Screening Survey Questions

For women who are not pregnant

1. In the past 3 months, have you smoked cigarettes?
2. Do you use a seatbelt every time you ride in a motor vehicle?
3. Do you exercise three or more times per week?
4. In the past 3 months, about how many days a week did you have two or more standard drinks (a standard drink is one 12-ounce bottle or can of beer or wine cooler, one 1.5-ounce shot of hard liquor, or one 5-ounce glass of wine)?
5. In the past 3 months, about how many days a week did you have four or more standard drinks?
6. How many drinks does it take to make you feel high?
7. Have any family members, friends, or health care professionals been concerned about how much you drank in the last year?

Scoring: Based on questions 4–7, score positive if patient:

- Admits to drinking almost every day.
- Admits to drinking four or more drinks per occasion.
- Reports that it takes more than two drinks to get high.
- Reports that family members or friends are concerned about her alcohol use.

Any positive score is followed by nine questions to assess risk for alcohol-associated problems:

1. Have you ever felt the need to cut down or control your drinking?
2. Have you ever lost a job because of your drinking?
3. Has your drinking affected your family, especially your children?
4. Have you ever been stopped by the police when you were drinking?
5. Have you been injured when you were drinking?
6. Do you become very nervous or shaky if you stop drinking for more than a day?
7. Do you need to have a drink in the morning to start your day?
8. Do you have medical problems that could be related to alcohol use, such as depression, suicide ideation, anxiety, panic attacks, sleeping problems, headaches, and chronic fatigue? More serious medical problems might include liver dysfunction, repeated trauma, blood pressure elevation, and pancreatitis.
9. Do you have evidence of alcohol problems on physical exams, such as high blood pressure, cardiac arrhythmia, enlarged liver, or alcohol on your breath?

Scoring:

Patient is an at-risk drinker—negative response to the nine assessment questions above and is only positive on the Health Screening Survey.
Patient is a problem drinker—one or two positive responses.
Patient might be alcohol dependent—three or more positive responses.

Patients who are at-risk or problem drinkers should receive brief intervention. Patients who might be alcohol-dependent should receive brief intervention and be referred to specialized treatment.

For women who are pregnant

1. In the past 3 months, have you smoked cigarettes?
2. Do you use a seatbelt every time you ride in a motor vehicle?
3. Do you exercise three or more times per week?
4. In the past 3 months, about how many days a week did you have two or more standard drinks (a standard drink is one 12-ounce bottle or can of beer or wine cooler, one 1.5-ounce shot of hard liquor, or one 5-ounce glass of wine)?
5. How many drinks does it take to make you feel high?
6. Have any family members, friends, or health care professionals been concerned about how much you drank in the last year?
7. Since you became pregnant, on average, about how many days a week do you have two or more standard drinks?

Scoring: Based on questions 4–7, score positive if patient:

- Admits to drinking almost every day during pregnancy.
- Reports that it takes more than 2 drinks to get high.
- Reports that family members or friends are concerned about her alcohol use.
- Reports drinking 2 or more drinks per day two or more days per week during pregnancy.

Any positive score is followed by the nine questions to assess risk for alcohol-associated problems.

Scoring:

Patient is an at-risk drinker—negative response to the nine assessment questions above and is only positive on the Health Screening Survey.
Patient is a problem drinker—one or two positive responses.
Patient might be alcohol dependent —three or more positive responses.

Patients who are at-risk or problem drinkers should receive brief intervention. Patients who might be alcohol-dependent should receive brief intervention and be referred to specialized treatment.

For more information on this publication please contact: NIAAA Publication Distribution Center, PO Box 10686, Rockville MD 20949-0686 (NIH Publication No. 99-4368) or order online at http://www/niaaa.nih.gov/.

VI. Definition of Risk Drinking

Mary J. O'Connor, PhD; R. Louise Floyd, DSN; and Gretchen Guiton, PhD

Following are types of drinkers by patterns of alcohol use (NIAAA, 1999):

- **Abstainers:** Do not consume alcohol at all or have less than 1 drink per month.
- **Low-risk drinkers:** Consume 1–2 standard drinks per day, but only 3 or fewer times per week. Their use of alcohol does not affect their health, and it does not result in problems. They do not use alcohol before driving, when pregnant, when breastfeeding, or with certain medications.
- **At-risk drinkers:** Consume 7–21 standard drinks per week; consume more than 3–4 standards drinks per occasion or drink in risky situations.
- **Problem drinkers:** Consume more than 21 standard drinks per week and might experience problems from such drinking (behavioral, family, medical, mental health, employment, social, legal).
- **Alcohol-dependent drinkers:** Cannot stop drinking once they start. They experience repeated and multiple problems from such drinking (behavioral, family, medical, mental health, employment, social, legal). Heavy drinking leads to a physical need for alcohol.

VII. Criteria for Referral to Treatment

Mary J. O'Connor, PhD; R. Louise Floyd, DSN; and Gretchen Guiton, PhD

Please refer to the NIAAA Health Screening Survey for criteria (NIAAA,1997).

A. Women Who Are Not Pregnant

- **Patient is an at-risk drinker.** One positive response on the Health Screening Survey and negative responses to the nine assessment questions having to do with consequences of drinking (behavioral, family, medical, mental health, employment, social, legal).
- **Patient is a problem drinker.** Positive responses on the Health Screening Survey and one or two positive responses on the assessment questions.
- **Patient might be alcohol-dependent.** Positive responses on the Health Screening Survey and three or more positive responses on the assessment questions.

Women who are at-risk or problem drinkers should receive brief intervention. Women who might be alcohol-dependent should receive brief intervention and be referred to specialized treatment.

B. Women Who Are Pregnant

- **Patient is an at-risk drinker.** One positive response on the Health Screening Survey and negative responses to the nine assessment questions having to do with consequences of drinking (behavioral, family, medical, mental health, employment, social, legal).
- **Patient is a problem drinker.** Positive responses on the Health Screening Survey and one or two positive responses on the assessment questions.
- **Patient might be alcohol-dependent.** Positive responses on the Health Screening Survey and three or more positive responses on the assessment questions.

Pregnant women who are at-risk or problem drinkers should receive brief intervention. Those who might be alcohol-dependent should receive brief intervention and be referred to specialized treatment.

Suggested Learning Activities

- Assign topics using section headers (nursing mothers, etc.) for small groups to research and present to the group. Include target populations who should be screened, suggested approaches, and opportunities.
- Lead a group discussion of barriers and opportunities for screening.
- Use a brief screening tool, such as TWEAK, in a role play activity. Follow up with group discussion. Use brief intake information for the group that increases a woman's risk for alcohol use.
- Use case studies of women with different risk factors for group discussion.
- Role play screening techniques. Provide scripted information for the role of the woman being screened. Activities would include assessment of quantity and frequency of alcohol as well as selection of appropriate tool.
- Explore ACOG's *Drinking and Reproductive Health: A Fetal Alcohol Spectrum Disorders Prevention Tool Kit* (http://www.acog.org/from_home/misc/dept_pubs.cfm).
- Demonstrate screening and brief intervention techniques using the ACOG tool kit. (http://www.acog.org/from_home/misc/dept_pubs.cfm).
- Use a group discussion to explore factors to consider in selecting a screening tool.
- Role play or use standardized patient to conduct the Health Interview for Women.
- Create a matching activity with drinking description to types of drinks.
- Use mini case studies or scenarios of women for group discussion of type of drinker.
- Use mini case studies or scenarios to identify need for referral to treatment.

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Learning Goals and Related Objectives

Goal II-A: Screen women of childbearing age for alcohol use at the appropriate time during patient care

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Explain the importance of monitoring women's alcohol consumption. (A) ▪ Recognize that all women of childbearing age should be screened for alcohol use. (K)	▪ Identify screening of women's alcohol use as an important part of routine clinical care. (A) ▪ Differentiate the need for and approaches to screening women of different ages and cultural backgrounds. (K) ▪ Identify opportunities to screen women for alcohol use in individual practice settings. (K) ▪ Establish procedures for screening all women of childbearing age for alcohol use. (S)	▪ Describe the need for ongoing monitoring of all women's alcohol consumption. (A) ▪ State the most current approaches for screening in multiple settings. (K) ▪ Demonstrate knowledge of different techniques that are appropriate for women of different ages and cultural backgrounds. (K) ▪ Explain procedures to ensure that all women of childbearing age receive appropriate alcohol screening. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal II-B: Use demographic and other risk factors appropriately in prevention and screening activities

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Recognize the increased need to screen women with characteristics associated with greater risk for alcohol use. (A) ▪ Identify features that increase a woman's risk for alcohol use, including age, marital status, level of education, family history, acculturation, and socioeconomic and cultural factors. (K) ▪ Demonstrate the ability to collect basic demographic and personal information from a woman to assess risk for alcohol use. (S)	▪ Describe the potential problems associated with stereotypical thinking about demographic or socio-cultural factors related to risk for alcohol use. (A) ▪ Explain the importance of accepting differences in women's attitudes about alcohol consumption depending on their socio-cultural background. (A) ▪ Recognize interaction of multiple factors as contributors to a woman's risk for alcohol use. (K) ▪ Identify level of risk in specific practice settings. (K) ▪ Describe subtle signs of alcohol use (e.g., frequent injuries). (K) ▪ Obtain comprehensive demographic and personal information from a woman to assess risk for alcohol use. (S) ▪ Evaluate risk factors accurately for the population the practitioner serves. (S)	▪ State the limitations of current risk factors for identifying women who use alcohol. (A) ▪ Explain current research developments refining risk factors. (K) ▪ Identify additional information about risk factors and implement new criteria when available. (S) ▪ Describe research developments refining risk factors. (S) ▪ Describe risk factors in concrete ways for practitioners. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal II-C: Use screening methods, screening tools, and assessment methods appropriately as part of prevention and screening activities

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Explain the importance of screening women for alcohol use. (A) ▪ Show awareness of own level of comfort in asking alcohol use questions. (A) ▪ Explain the treatment benefits of screening. (A) ▪ Describe primary screening components (e.g., quantity/ frequency, binge drinking, and AA). (K) ▪ Recognize drinking that meets criteria for a binge episode. (K) ▪ Categorize women's risk according to level of alcohol consumed. (K) ▪ Define standard drink. (K) ▪ Recognize the link between method of question administration and likelihood of woman's disclosure of alcohol use. (K) ▪ Identify multiple screening tools, including laboratory methods, and differences among them. (K) ▪ Demonstrate the ability to ask TWEAK or T-ACE questions as a routine part of history taking with women of childbearing age. (S) ▪ Assess alcohol consumption patterns based on a woman's responses. (S)	▪ Demonstrate an underlying attitude of respect for women who are using alcohol. (A) ▪ Express comfort in working with women who use alcohol. (A) ▪ Demonstrate empathy for women who use alcohol. (A) ▪ Identify methods to increase reliability and validity of screening questions (e.g., specific types of alcoholic beverages consumed, accurate alcohol content estimates, vessel sizes). (K) ▪ Select the best screening method for a specific context (e.g., patient background, culture, relationship, time available). (K) ▪ Differentiate risk criteria depending on a woman's pregnancy status (i.e., binge level, drinks/wk). (K) ▪ Differentiate need for referral based on a woman's drinking status. (K) ▪ Locate treatment referral resources. (K) ▪ Conduct comprehensive interview of a woman regarding alcohol use. (S) ▪ Assess a woman for high-risk drinking. (S) ▪ Assess a woman for referral to more intensive treatment program. (S) ▪ Communicate the definition of a standard drink to a woman. (S)	▪ Describe sources for criteria of alcohol use that constitute abuse and risk for FASDs and how to access them. (K) ▪ Use resources and research efforts to refine and/or develop improved methods of screening and assessing alcohol use in pregnant women. (K) ▪ Evaluate new screening methods using evidence-based criteria. (S) ▪ Demonstrate use of screening tools to practitioners including description of when, how, and with whom to use. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal II-D: Conduct brief interventions with women

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Identify distinguishing features of brief interventions. (K) ▪ Describe benefits of brief interventions. (K) ▪ List questions to determine a woman's readiness to change drinking behavior. (K) ▪ Define steps in conducting brief intervention. (K) ▪ Demonstrate the ability to interview a woman without criticism or provocation of guilt. (S) ▪ Articulate benefits of stopping or reducing drinking. (S) ▪ Provide normative information about drinking behaviors. (S)	▪ Demonstrate a nonjudgmental attitude about women's drinking. (A) ▪ Display an underlying attitude of respect for women who are using alcohol. (A) ▪ Express comfort in working with women who use alcohol. (A) ▪ Demonstrate empathy for women who use alcohol. (A) ▪ Display comfort in conducting brief intervention with women from diverse backgrounds seen frequently in practice setting. (A) ▪ Recognize demographic and environmental factors that might impede success of brief intervention. (K) ▪ Describe brief intervention techniques. (K) ▪ Explain the efficacy of brief intervention techniques. (K) ▪ Develop a brief intervention plan for a specific woman. (S) ▪ Tailor brief intervention for women of different socioeconomic, educational, or cultural backgrounds. (S) ▪ Provide clear concrete feedback to a woman using examples, visual displays, etc. (S) ▪ Conduct brief intervention with women. (S) ▪ Motivate a woman's desire to reduce or stop drinking. (S) ▪ Support a woman's efforts to reduce or stop drinking. (S)	▪ Identify sources of new intervention research and how to access them. (K) ▪ Explain evidence-based criteria for evaluating interventions. (K) ▪ Describe national research efforts to improve treatment using brief intervention. (K) ▪ Evaluate new intervention methods using evidence-based criteria. (S) ▪ Demonstrate new methods to other practitioners. (S) ▪ Assist practitioners in confronting their own biases in working with women who use alcohol. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal II-E: Appreciate the use of more extensive interviews to evaluate alcohol consumption during pregnancy

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe the use of more extensive interviews to evaluate alcohol consumption during pregnancy. (K)	▪ Conduct the Health Interview for Women with pregnant women. (S) ▪ Conduct the NIAAA Health Screening Survey with non-pregnant women of childbearing age and pregnant women. (S)	▪ Explain to others the use of more extensive interviews to evaluate alcohol consumption during pregnancy. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal II-F: Define risk drinking and differentiate types of drinkers by patterns of alcohol use

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Differentiate the types of drinkers by patterns of alcohol use. (K)	▪ Identify types of drinkers by patterns of alcohol use. (S)	▪ Explain to other health professionals how to differentiate types of drinkers by patterns of alcohol use. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal II-G: Assess for referral to treatment

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Explain the need to assess a woman for referral to more intensive treatment programs. (K)	▪ Assess a woman for referral to more intensive treatment programs. (S)	▪ Explain to others about the need to assess a woman for referral to more intensive treatment programs. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Competency III: Models of Addiction

The health care student or provider will be able to apply concepts and models of addiction to women of childbearing age, including those who are pregnant, to provide appropriate prevention services, referral, and case management.

Learning Goals

(Learning objectives for each goal can be found at the end of this section.)

III-A Explain past and current models of alcohol use.
III-B Describe the categories of alcohol use in women.
III-C Describe stages of alcohol use, dependence, and addiction.
III-D Explain the stages of change in alcohol use.
III-E Address co-occurring psychiatric disorders related to alcohol use.
III-F Recognize characteristics of alcohol-dependent families.

Content Outline for Competency III

I. **Past and current models of alcohol use**
II. **Categories of alcohol use in women**
III. **Stages of alcohol use, dependence, and addiction**
   A. Medical criteria for alcohol use disorders
   B. Stages of use
IV. **Stages of change in alcohol use**
V. **Alcohol and co-occurring psychiatric disorders**
VI. **Characteristics of alcohol-dependent families**
   A. Role of genetics
   B. Family factors that might contribute to alcohol use

Also included in this section are:

- Suggested learning activities.
- References and additional readings/resources.
- Chart of all learning goals and objectives for this competency.

I. Past and Current Models of Alcohol Use

Susan Adubato, PhD; Kathleen Mitchell, MHS, LCADC; and Tara Rupp

Alcohol-related problems have been defined in many ways through history, depending on the political and social times. How we conceptualize a problem greatly influences how we treat it. While the most accepted model in the science community is a biomedical model, other models still have many proponents and provide alternative perspectives about how people think about and address alcohol issues. Some models were more prevalent historically, and some are still prevalent today. It should be noted that all of these models still might be used by some professionals today (Center for Substance Abuse Treatment, 1999; Rogers & McMillin, 1988).

1. **Moral model.** One of the first models of alcoholism, the moral model emphasized a personal choice as a cause of the problem. Here, someone who is alcohol dependent, typically referred to as "alcoholic" in this model, chooses whether to drink or to abstain. Proponents of the moral model see the alcoholic individual as unable or unwilling to "do the right thing" and as making choices in violation of societal norms and morals. Health care professionals and families who adhere to this model believe that the person doesn't have the moral strength to resist alcohol's temptation. Treatment consists of the individual's recognizing the "sinfulness" of his or her state, asking for help, accepting punishment from the moral authorities and, once forgiven, being allowed back into society. No treatment, per se, is prescribed in this model. Punishment of the alcoholic behavior is important. The sole blame for alcoholism is on the alcohol-dependent individual.

2. **Sociocultural models.** A number of similar models promote the belief that alcohol (and drug) abuse is facilitated by society. Influencing factors include a lack of economic opportunity and positive role models in some geographic regions or among some groups of people. Additionally, in this model, social norms marginalize people who use drugs and abuse alcohol, and such marginalization leads to alcohol and drug peer networks that then provide social reinforcement. Treatment involves education, economic opportunity, and reintegration back into society.

3. **Psychological models.** A variety of related models are based on the idea that heavy drinking is promoted from observing others. Children, therefore, learn that drinking is an effective means of dealing with stress or enjoying social situations. Drinking is viewed as a way to numb emotional pain or achieve pleasure. Proponents of this model are likely to view alcohol and other substance use problems as indicative of a lack of other coping skills to deal with stress. Treatment involves learning positive coping skills, reducing stressors, and resolving other psychological and emotional problems.

   The conditioning model, a cousin of the psychological models, purports that people learn to drink because it is reinforced. In the conditioning model, treatment relies on classical conditioning (usually aversive therapies) in which drinking is punished and abstaining is rewarded.

4. **Addictive disease model.** This model is sometimes confused with the biomedical model. The addictive disease model promotes the idea that addiction is a primary disease that is

progressive and incurable. The disease exists because of biological, personality, and spiritual dysfunction. A loss of control over alcohol and denial that one has an alcohol problem are indicators of the disease. Abstinence is the necessary first step for treatment. The Alcoholics Anonymous approach to treatment is based on this model. Other options include outpatient and residential detoxification.

5. **Biomedical model.** This model is most widely supported by the scientific literature. It is based on the idea that alcohol dependence is a brain disorder, related to dysfunction of neurotransmitters (most likely a mixture of dopamine, serotonin, GABA, and glutamate). There is both a genetic and environmental basis for dependency. Alcohol (and other drugs) is abused because it stimulates the reward pathway in the brain. Proponents of this approach might think abstinence is advisable but not see it as necessary for all people with dependency, favoring instead a harm-reduction approach, drug substitution, craving reduction medication, and brief psychotherapy, such as motivational interviewing and cognitive behavioral approaches.

Table 3.1 provides a definition of alcoholism developed by the Joint Committee to Study the Definition and Criteria for the Diagnosis of Alcoholism of the National Council on Alcoholism and Drug Dependence and the American Society of Addictive Medicine. Table 3.2 outlines the addictive disease process.

Table 3.1. Definition of Alcoholism

"Alcoholism is a primary, chronic disease with genetic, psychosocial, and environmental factors influencing its development and manifestations. The disease is often progressive and fatal. It is characterized by continuous or periodic impaired control over drinking, preoccupation with the drug alcohol, use of alcohol despite adverse consequences, and distortions in thinking, most notably denial."

"Primary" refers to the nature of alcoholism as a disease entity in addition to and separate from other pathophysiologic states that may be associated with it.

"Primary" suggests that alcoholism, as an addiction, is not a symptom of an underlying disease state.

"Disease" means an involuntary disability. It represents the sum of the abnormal phenomena displayed by a group of individuals. These phenomena are associated with a specified common set of characteristics by which these individuals differ from the norm, and which places them at a disadvantage.

"Often progressive and fatal" means that the disease persists over time and that physical, emotional, and social changes are often cumulative and may progress as drinking continues. Alcoholism causes premature death through overdose; through organic complications involving the brain, liver, heart, and many other organs; and by contributing to suicide, homicide, motor vehicle crashes, and other traumatic events.

"Impaired control" means the inability to limit alcohol use or to consistently limit on any drinking occasion the duration of the episode, the quantity consumed, and/or the behavioral consequences of drinking.

"Preoccupation" in association with alcohol use indicates excessive, focused attention given to the drug alcohol, its effects, and/or its use. The relative value thus assigned to alcohol by the individual often leads to a diversion of energies away from important life concerns.

"Adverse consequences" are alcohol-related problems or impairments in such areas as physical health (e.g., alcohol withdrawal syndromes, liver disease, gastritis, anemia, neurological disorders); psychological functioning (e.g., impairments in cognition, changes in mood and behavior); interpersonal functioning (e.g., marital problems and child abuse, impaired social relationships); occupational functioning (e.g., school or job problems); and legal, financial, or spiritual problems.

"Denial" is used here not only in the psychoanalytic sense of a single psychological defense mechanism disavowing the significance of events, but more broadly to include a range of psychological maneuvers designed to reduce awareness of the fact that alcohol use is the cause of an individual's problems rather than a solution to those problems. Denial becomes an integral part of the disease and a major obstacle to recovery.

This definition was prepared by the Joint Committee to Study the Definition and Criteria for the Diagnosis of Alcoholism of the National Council on Alcoholism and Drug Dependence and the American Society of Addiction Medicine. Approved by the Boards of Directors of the National Council on Alcoholism and Drug Dependence, Inc. (February 3, 1990) and the American Society of Addiction Medicine (February 25, 1990).

Table 3.2. Addictive Disease Process

Addictive disease process is a chronic, primary progressive disease characterized by:

A. Craving and compulsion.
B. Loss of control.
C. Continued use despite adverse consequences.

A. Craving and Compulsion

- Mildest form of craving is vivid dreams about the pleasures of use.
- More pronounced craving—thinking about how nice the drug was.
- Preoccupation on planning the next opportunity to use the drug (unable to stay in the now).
- Actual physical hunger for the drug (withdrawal).

B. Loss of Control

- Amount: Becomes increasingly less able to predict the amount of drug one will use once started. Has difficulty "saving" some of the drug for later use. As disease progresses, larger amounts of drug are needed to satisfy increasing desire.
- Time and place: Finds it difficult to confine use to times and place.
- Duration of episode: May use drug until it's all gone, which prevents other activities, i.e., missing time from work and neglecting obligations, family and/or financial.

C. Continued Use Despite Adverse Consequences

- May affect areas of life: legal, family, health, occupational, sexual, social.
- Drug use patterns:
  1. Variety of drugs.
  2. Alternating drug of choice.
  3. Over lifetime, progression towards more severe involvement.

Since the addictive disease process is both chronic and progressive, one assumes that it will continue to grow steadily if it is not arrested.

Source: Mitchell, K. T. (2003, September). Presented at "Hope for Women in Recovery: Understanding and Addressing the Impact of Prenatal Alcohol Exposure," Baltimore, Maryland.

II. Categories of Alcohol Use in Women

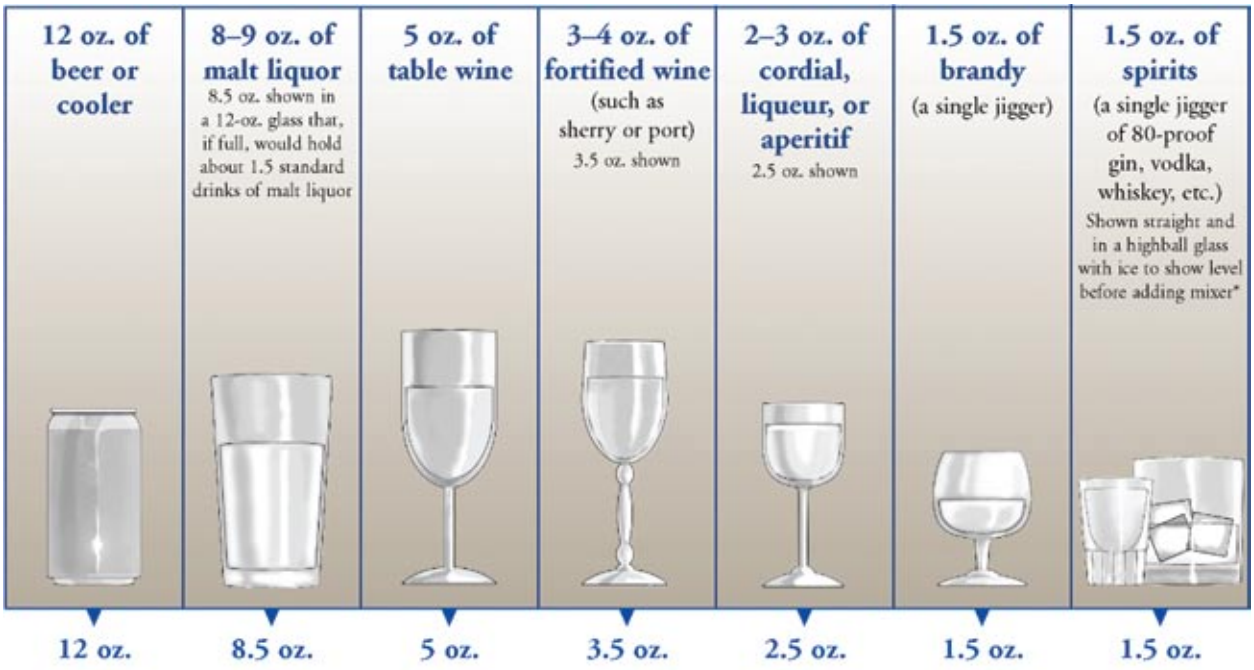
Susan Adubato, PhD; Kathleen Mitchell, MHS, LCADC; and Tara Rupp

More than half of all women of childbearing age (18–44 years) report some alcohol use, and one in eight reports binge drinking in the past month (Centers for Disease Control and Prevention [CDC], 2002). Many of these women are sexually active and are often not taking effective measures to prevent pregnancy. These women are at high risk for an alcohol-exposed pregnancy (AEP) as they might continue drinking early in pregnancy at levels that are harmful to the fetus (U. S. Department of Agriculture & U.S. Department of Health and Human Services, 2000).

Although most women reduce alcohol consumption after learning that they are pregnant (CDC, 1995), in the United States, 10% of pregnant women report consuming any alcohol and 2%–4% report binge drinking (Tsai & Floyd, 2004; Substance Abuse and Mental Health Services Administration [SAMHSA], 2002). In these findings, binge drinking was defined as consuming five or more drinks on any one occasion. More recently, the definition of binge drinking for women has been changed to four or more drinks on any one occasion (National Institute on Alcohol Abuse and Alcoholism [NIAAA], 2005).

Traditionally, all drinks have been considered equivalent in terms of the amount of absolute alcohol. A standard drink contains about 14 grams (about 0.6 fluid ounces) of pure alcohol, which is equivalent to one 12-ounce beer or wine cooler, one 5-ounce glass of wine, or 1.50 ounces of 80-proof distilled spirits. However, people buy many alcoholic drinks in containers that hold multiple standard drinks. For example, malt liquor is often sold in 16-, 22-, or 40-ounce containers that hold between two and five standard drinks, and table wine is typically sold in 25-ounce (750 ml.) bottles that hold five standard drinks. Figure 3.1 shows approximate standard drink equivalents of common alcoholic drinks.

Figure 3.1. Standard Drink



Source: National Institute on Alcohol Abuse and Alcoholism. (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.

Women fall into one of the following categories with regard to alcohol use (NIAAA, 1999):

1. **Abstainers.** Do consume no alcohol at all or less than 1 drink per month.

2. **Low-risk drinkers.** Consume 1–2 standard drinks per day, three or fewer times per week. Their use of alcohol does not affect their health and it does not result in negative consequences. They do not use alcohol before driving, when pregnant, when breastfeeding, or with certain medications.

3. **At-risk drinkers.** Consume 7–21 standard drink per week; consume more than 3–4 standard drinks per occasion, or drink in high-risk situations.

4. **Problem drinkers.** Consume more than 21 standard drinks per week and might experience negative consequences from such drinking (behavioral, family, medical, mental health, employment, social, legal, etc.).

5. **Alcohol-dependent drinkers.** Cannot stop drinking once they start. They experience repeated negative consequences from such drinking (behavioral, family, medical, mental health, employment, social, legal, etc.). Heavy drinking leads to a physical need for alcohol.

Tables 3.3 and 3.4 show diagnostic criteria and sample assessment questions for alcohol abuse and alcohol dependence, respectively (more information will be found under DSM-IV criteria, in the next section).

Table 3.3. Alcohol Abuse: Diagnostic Criteria with Sample Questions for Assessment

One or more of the following occurring at any time in the same 12-month period (all questions prefaced by "In the past 12 months…"):

Failure to fulfill major role obligations at work, school, or home because of recurrent drinking

- Have you had a period when your drinking—or being sick from drinking—often interfered with taking care of your home or family? Caused job troubles? School problems?

Recurrent drinking in hazardous situations

- Have you more than once driven a car or other vehicle while you were drinking? Or after having had too much to drink?
- Have you gotten into situations while drinking or after drinking that increased your chances of getting hurt—like swimming, using machinery, or walking in a dangerous area or around heavy traffic?

Recurrent legal problems related to alcohol

- Have you gotten arrested, been held at a police station, or had any other legal problems because of your drinking?

Continued use despite recurrent interpersonal or social problems

- Have you continued to drink even though you knew it was causing you trouble with your family and friends?
- Have you gotten into physical fights while drinking or right after drinking?

Source: National Institute on Alcohol Abuse and Alcoholism. (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.

Table 3.4. Alcohol Dependence: Diagnostic Criteria with Sample Questions for Assessment

Three or more of the following, occurring at any time in the same 12-month period (all questions prefaced by "In the past 12 months…"):

Tolerance

- Have you found that you have to drink much more than you once did to get the effect you want? Or that your usual number of drinks has much less effect on you than it once did?

Withdrawal syndrome or drinking to relieve withdrawal

- When the effects of alcohol are wearing off, have you had trouble sleeping? Found yourself shaking? Nervous? Nauseated? Restless? Sweating or with your heart beating fast? Have you sensed things that aren't really there? Had seizures?
- Have you taken a drink or used any drug or medicine (other than over-the-counter pain relievers) to keep from having bad after-effects of drinking? Or to get over them?

Impaired control

- Have you more than once wanted to stop or cut down on your drinking? Or tried more than once to stop or cut down but found you couldn't?

Drank more or longer than intended

- Have you had times when you ended up drinking more than you meant to? Or kept on drinking for longer than you intended?

Neglect of activities

- In order to drink, have you given up or cut down on activities that were important or interesting to you or gave you pleasure?

Time spent related to drinking or recovering

- Have you had a period when you spent a lot of time drinking? Or being sick or getting over the bad after-effects of drinking?

Continued use despite recurrent psychological or physical problems

- Have you continued to drink even though you knew it was making you feel depressed or anxious? Or causing a health problem or making one worse? Or after having a blackout?

Source: National Institute on Alcohol Abuse and Alcoholism. (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.

III. Stages of Alcohol Use, Dependence, and Addiction

Susan Adubato, PhD; Kathleen Mitchell, MHS, LCADC; and Tara Rupp

A. Medical Criteria for Alcohol Use Disorders

The American Medical Association recognized alcoholism as a disease in 1956. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), as many as 90% of the adults in the United States have had some experience with alcohol. Of these adults, 60% of men and 30% of women have had one or more "alcohol-related adverse life event," such as missing work due to a hangover or driving while intoxicated (American Psychiatric Association [APA], 2000).

Following are the DSM-IV (APA, 2000) criteria for alcohol-related disorders. It should be noted that in addition to these criteria, generic aspects of substance abuse and dependence can be found in the DSM-IV criteria for those specific issues (Table 3.5).

303.90 — **Alcohol Dependence.** Individuals with alcohol dependence continue to consume alcohol, regardless of adverse consequences, usually to avoid or relieve the withdrawal symptoms. Approximately 5% of the individuals with alcohol dependence will experience true alcohol withdrawal and its complications. A primary mental disorder should be considered when symptoms persist.

305.00 — **Alcohol Abuse.** When individuals abuse alcohol, many facets of their lives can be affected. They might experience problems in school or with their job performance; neglect the care of their family; put themselves in hazardous situations, such as driving while intoxicated or using machinery while drunk; and face legal problems as a result of their continued drinking. If an individual experiences tolerance, withdrawal, or compulsive behavior as well, one should consider a diagnosis of alcohol dependence.

303.00 — **Alcohol Intoxication.** Here, the essential feature is the presence of "significantly maladaptive behavioral or psychological changes…" (APA, 2000, p. 196) that develop during, or shortly after, the use of alcohol. Instances of sexually inappropriate behavior, impaired judgment, or social functioning also are evident. See Table 3.6 for full diagnostic criteria. Evidence of use is usually obtained by the smell of alcohol on the person's breath, doing a blood and urine toxicology analysis, and taking a history of use.

291.81 — **Alcohol Withdrawal.** Here, the essential feature is withdrawal symptoms that develop after one stops heavy and prolonged alcohol use. Table 3.7 presents the full criteria. If hallucinations or illusions are also observed, one can specify "with perceptual disturbances." Symptoms usually are relieved by the consumption of alcohol, or any other "brain depressant." The symptoms are evident usually within 4–12 hours of cessation of alcohol use, but can last for days. Because of the short half-life of alcohol, withdrawal usually peaks by day 2 and will be markedly improved by the fourth or fifth day. After initial withdrawal, however, some physiological symptoms, such as insomnia and anxiety, can last for months. Dramatic symptoms, such as delirium, usually occur in only 5% of individuals with alcohol withdrawal.

Table 3.5. Alcohol-Induced Disorders

291.0	Alcohol Intoxication Delirium
291.0	Alcohol Withdrawal Delirium
291.2	Alcohol-Induced Persisting Dementia
291.1	Alcohol-Induced Persisting Amnestic Disorder
291.5	Alcohol-Induced Psychotic Disorder, with Delusions Specify if: With Onset During Intoxication/With Onset During Withdrawal
291.3	Alcohol-Induced Psychotic Disorder, with Hallucinations Specify if: With Onset During Intoxication/With Onset During Withdrawal
291.89	Alcohol-Induced Anxiety Disorder Specify if: With Onset During Intoxication/With Onset During Withdrawal
291.89	Alcohol-Induced Mood Disorder Specify if: With Onset During Intoxication/With Onset During Withdrawal
291.89	Alcohol-Induced Sexual Dysfunction Specify if: With Onset During Intoxication
291.89	Alcohol-Induced Sleep Disorder Specify if: With Onset During Intoxication/With Onset During Withdrawal
291.9	Alcohol-Related Disorder Not Otherwise Specified

Source: American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)*. Washington, D.C.: American Psychiatric Association.

Table 3.6. Diagnostic Criteria for 303.00 Alcohol Intoxication

A. Recent ingestion of alcohol.

B. Clinically significant maladaptive behavioral or psychological changes (e.g., inappropriate sexual or aggressive behavior, mood liability, impaired judgment, impaired social or occupational functioning) that developed during, or shortly after, alcohol ingestion.

C. One (or more) of the following signs, developing during, or shortly after, alcohol use:

- slurred speech
- incoordination
- unsteady gait
- nystagmus
- impairment in attention or memory
- stupor or coma

D. The symptoms are not due to a general medical condition and are not better accounted for by another medical disorder.

Source: American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)*. Washington, D.C.: American Psychiatric Association.

Table 3.7. Diagnostic Criteria for 291.81 Alcohol Withdrawal

A. Cessation of (or reduction in) alcohol use that has been heavy and prolonged.

B. Two (or more) of the following, developing within several hours to a few days after criterion A:

- autonomic hyperactivity (e.g., sweating or pulse rate greater than 100)
- increased hand tremor
- insomnia
- nausea or vomiting
- transient visual, tactile, or auditory hallucinations or illusions
- psychomotor agitation
- anxiety
- grand mal seizures

C. The symptoms in Criterion B cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

D. The symptoms are not due to a general medical condition and are not better accounted for by another medical disorder.

Specify if: With Perceptual Disturbances

Source: American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)*. Washington, D.C.: American Psychiatric Association.

B. Stages of Use

There is a definite pattern of symptoms and progression of alcohol abuse and addiction, in terms of increasing dysfunction. The following presents the three primary stages of alcohol use, dependence, and addiction (See also Table 3.8).

1. **Tolerance.** Tolerance is the ability to drink without becoming intoxicated. Alcohol tolerance usually indicates the presence of alcoholism, or eventually becoming alcoholic—although not everyone with high tolerance will become an alcoholic. It represents the physical adaptation to the intoxicating properties of alcohol. The development of alcohol tolerance has relatively nothing to do with a person's weight. Tolerance progressively increases in that it takes more and more alcohol to give the same result. In this stage, the use of alcohol usually is socially motivated, and the individual seeks psychological relief by drinking. The "advantage" of tolerance is that it allows the alcoholic to hide the extent of his or her drinking after the appearance of the second stage.

2. **Physical dependency.** Physical dependence on alcohol motivates the large bulk of alcoholic drinking. Once withdrawal begins, the alcoholic drinks more to alleviate or eliminate the symptoms. When one drinks continually, for no reason other than to drink, it is the physical dependency, and the last drink has "worn off." In this stage, an individual might experience blackouts, sneak drinks, gulp down alcohol, and feel guilty about drinking.

3. **Major organ change.** Major organ change is seen when alcohol has done measurable damage to the body. It can be an enlarged liver, kidney and pancreas problems, and a whole range of alcohol-related health problems. The effects of alcohol on organs are the most debilitating of any substance. Physical damage plays a key role in alcoholic behavior and in the progression of alcoholism.

Treatments. Many options for treatment exist, depending on the stage of the alcohol use. Alcohol dependence is usually treated through withdrawal and detoxification, followed by further interventions to maintain abstinence. Severity of withdrawal symptoms increases with each withdrawal episode. Severe withdrawal occurs in 2%–5% of all heavy drinkers and chronic alcoholics. It could last for 3–7 days. Death, which occurs in less than 1%, occurs when there is cardiovascular collapse or concurrent infection. The use of benzodiazepines and phenobarbital reduces the risk of seizures when individuals are medically withdrawn. Individuals are usually admitted to a hospital or treatment center for detoxification. Long-lasting neurobiologic effects contribute to the persistence of the craving. Relapse can be triggered at any stage of the recovery by internal or external factors. Thus, health care providers must help the individual understand, anticipate, and prevent relapse.

Other interventions used include:

- Alcoholics Anonymous and 12-step facilitation therapy—12 steps to work through during recovery (Alcoholics Anonymous, 2007).
- Cognitive-behavior therapy—teaches individuals, through role-play and rehearsal, to recognize and cope with situations for relapse, and how to cope with cravings (Center for Substance Abuse Treatment, 1997, 2005).

- Motivational enhancement therapy (MET)—motivates patients to use their own resources to change their behavior. This is considered brief intervention and works best with social drinkers (Center for Substance Abuse Treatment, 1999, 2005).
- Pharmacotherapy—use of anticraving medications (e.g., acamprosate and naltrexone), aversive medications (e.g., disulfiram) and medications to treat the co-morbidities (e.g., Prozac) (National Institute on Alcohol Abuse and Alcoholism [NIAAA], 2005). Other compounds, currently approved for other medical issues, are being tested in clinical trials and have so far shown some efficacy as treatment for alcohol dependence. Further outcomes are pending (Johnson et al., 2007).

A 2006 randomized controlled trial comparing various combinations of drug therapy (acamprosate and naltrexone), behavior therapy, or both, showed that patients with alcohol dependency had better outcomes if given naltrexone (100 mg/day), behavioral intervention, or both. Acamprosate showed no evidence of efficacy, even with behavioral therapy. No combination was better than treatment with naltrexone alone or behavioral therapy alone, in the presence of medical management. These findings suggest that treatment for alcohol-dependent individuals could be delivered in the primary care setting (Anton et al., 2006).

Table 3.8. Primary Stages of Alcohol Use, Dependency, and Addiction

Stage I Tolerance (Early)	**Stage 2 Physical Dependency (Middle)**	**Stage 3 Major Organ Change (Late)**
Occasional use	A.M. use, daily use	Maintenance use
One drug, two gateway drugs (nicotine, alcohol, marijuana)	Variety of drugs	Multiple drug addiction
Tolerance	Increased tolerance	Change in tolerance
Occasional hangover	Withdrawal headaches, nausea	Migraine, vomiting
Anxiousness	Irritability, mood swings, paranoia	Mood disorder, paranoid disorders
Disrupted sleep patterns	Sleeplessness	Insomnia
Mild depression	Depression, institutions, psychiatric diagnosis, Rx	Suicidal ideation or attempts
Colds, infections	Disease pathology developing	Major organ damage
Increased sexual pleasure (reduced inhibitions)	Sexual problems	Impotence or sexual dysfunction
Mild tremors or shakes	Intention tremors	DTs (delirium tremors)
Vivid dreams	Nightmares	Night sweats
Memories of how nice the use was	Preoccupation, craving	Compulsion, use despite consequences
Occasional blackouts (memory loss)	Development of blackout patterns	Longer, more frequent duration of memory loss (weeks or months)
Outside Influences		
Family problems	School or work problems	Loss of job, family, school
In trouble with the law (close calls)	DWI/DUI possession	Incarceration

Source: Mitchell, K. (2000). Adapted from Rogers, C. R., & McMillin, C. S. (1988). *Don't help: A positive guide to working with the alcoholic.* Seattle: Madrona Publishers.

IV. Stages of Change in Alcohol Use

Susan Adubato, PhD; Kathleen Mitchell, MHS, LCADC; and Tara Rupp

Much has been written about success and failure rates in helping patients change, identifying barriers to change, and improving outcomes. The stages of change model described below is an outgrowth of the smoking cessation research.

Behavior change is not a single, discrete event. Few people have an epiphany event that readily changes their behavior. Behavior change is seen as a process, with identifiable stages. One can take action at any point in the process to assist in change. This model shows that a person's behavior occurs gradually, with the individual moving from an uninterested/unaware state to deciding to change to making the necessary actions to maintain the new behavior. Relapses often occur and are part of the overall process.

The stages of change, as pertains to drinking, are as follows (Center for Substance Abuse Treatment, 1999; Zimmerman, Oslen, & Bosworth, 2000):

1. **Precontemplation.** In this stage, the woman does not even consider changing. She is still in denial of her drinking problem and will probably not seek advice. Typically, someone else perceives the alcohol problem in the woman; the woman herself does not. She will likely resist suggestions to change in this stage.

   Goal: The woman will begin to think about change. Here, the intervention must concentrate on trying just to engage the woman, increase belief that change is possible, address safety concerns, provide needed services, find the woman's strengths and capacity for change, and raise her awareness of the problem. Other models that could be helpful at this stage include motivational interviewing, Locus of Control, and the Health Belief Model (Glanz, Rimer, & Viswanath, 2008).

2. **Contemplation.** Here the woman has some awareness of her drinking problem but might be ambivalent about changing. She might reject change because she will need to give up enjoyable behavior. She might feel more of a sense of loss than perceived gain. Here, the woman needs to assess barriers to change (time, expense, hassle, fear, "I know I should stop drinking but…") as well as the beneficial results of the change.

   Goal: The woman will examine benefits and barriers. In this stage, the intervention must tip the balance in favor of change, giving reasons to change and risks of not changing, and strengthening the woman's sense of self-efficacy for change. She must self-assess values, strengths, and needs. Sometimes there is a coerced action to change. Successful treatment models for this stage include motivational interviewing/person-centered approach, positive reinforcement, asking open-ended questions to elicit self-motivational statements and goal-setting.

3. **Preparation.** Here the woman is ready to change and prepares to make a specific change. Changes might start small, growing as her determination to change increases. This is a window of opportunity when the woman has resolved her ambivalence enough to make the change.

Goal: In this stage, the intervention must assist the woman in matching appropriate and effective strategies. One should explore various options and their benefits and consequences. Set specific goals, steps to the goals, and resources that will be needed. Another treatment approach is cognitive-behavioral therapy.

4. **Action.** Now the woman is ready to engage in new behavior that will bring about the elimination of her alcohol use. Any action taken should be praised because it demonstrates a desire for and effort to change.

   Goal: In this stage, intervention should assist the woman in looking at her addiction and in identifying coping strategies to change, replace, or avoid triggers that lead to alcohol use. One can help the woman try out some strategies and evaluate their effectiveness. Steps taken should be small and incremental. Reward any small step of change, and estimate success. Other treatments include cognitive-behavioral therapies and a 12-step program.

5. **Maintenance/Relapse.** Here, the woman tries to sustain changes accomplished in the previous stage. This stage, obviously, is the hardest, because it involves incorporating the changes "over the long haul." Discouragement over occasional slips might stop progress, and the woman might want to give up. This is a natural part of the process.

   Goal: In this stage, one reviews goals, coping strategies, progress, and overall health and well-being. Constructing relapse roadmaps and crisis plans for relapse, identifying warning signs of possible relapse, and connecting the woman to support systems are crucial to this stage of change. One must understand that maintaining the new behavior occurs over time. Family members need to be an integral part of this process. Other treatment models include motivational interviewing, 12-step programs, and cognitive-behavioral therapies.

V. Alcohol and Co-Occurring Psychiatric Disorders

Susan Adubato, PhD; Kathleen Mitchell, MHS, LCADC; and Tara Rupp

Interest in the co-occurrence of alcohol use and psychiatric disorders is growing. If an individual has one or more disorders relating to alcohol use (or any substance use) and one or more mental disorders, they are said to have a co-occurring disorder. The diagnosis of the psychiatric disorder must be established independently, and not just a cluster of symptoms relating to the alcohol use. The term for "substance abuse," as well as any mental disorder, refers to all disorders described in the DSM-IV (Center for Substance Abuse Treatment, 2005).

Following are some findings relating to co-occurring disorders and alcohol use:

- Among adults with serious mental illness, 23.2% were alcohol dependent or abused alcohol (SAMHSA, 2003).
- In the 2002 National Survey on Drug Use and Health, serious mental illness was correlated with binge drinking (defined at the time as five or more drinks on one occasion). Among adults with serious mental illness, 28.8% reported binge drinking (SAMHSA, 2003).
- The National Comorbidity Study, conducted from 1990 to 1992, found that among survey respondents who said they had lifetime alcohol abuse or dependence, 53% also had one or more lifetime mental disorders (U.S. Department of Health and Human Services, 1995).
- Alcohol abuse is associated with 25%–50% of suicides; a co-morbidity of alcoholism and depression increases suicide risk (Center for Substance Abuse Treatment, 2005).
- The most common co-morbidities for women who drink are anxiety and mood disorders (Enoch & Goldman, 2002).
- Symptoms such as anxiety, agitation, and paranoia can be either manifestations of alcohol intoxication or symptoms of withdrawal (APA, 2000).
- Depression, anxiety, and insomnia usually either precede or accompany alcohol dependence (Flynn, Craddock, Luckey, Hubbard, & Dunteman, 1996).
- Alcohol dependence might be associated with mood disorders, anxiety disorders, and schizophrenia (APA, 2000).
- Antisocial personality disorder might also be associated with alcohol-related disorders (Flynn et al., 1996). This co-occurrence will increase the likelihood of criminal behavior. The DSM-IV reports that more than half of all murderers and their victims are believed to have been intoxicated with alcohol at the time of the murder (APA, 2000).
- Among adolescent alcohol users, one might find conduct disorder and repeated antisocial behavior, as well as depression and suicide, eating disorders, and hormonal differences (Center for Substance Abuse Treatment, 2005).

A thorough assessment of both the alcohol use and the mental disorder should be made to ensure proper intervention. Interventions might include psychopharmacology, individual or group counseling, cognitive-behavioral therapy, motivational enhancement therapy, family interventions,

12-step programs, and case management. Interventions might include outpatient or inpatient programming. Dual-diagnosis enhanced programs integrate the substance abuse and mental health treatment services (American Society of Addiction Medicine, 2001). Any intervention should be targeted at the management and resolution of acute symptoms, relapse, and long-term care. One also needs to remember cultural factors that might enhance or impede the assessment and intervention.

The Treatment Improvement Protocol (TIP) Series 42, *Substance Abuse Treatment for Persons with Co-Occurring Disorders*, provides a comprehensive overview, reference, and intervention protocol for best practices with treating individuals with co-occurring disorders (Center for Substance Abuse Treatment, 2005).

VI. Characteristics of Alcohol-Dependent Families

Susan Adubato, PhD; Kathleen Mitchell, MHS, LCADC; and Tara Rupp

The role that families have in the development of an addiction, specifically alcoholism, in an individual seems intuitive. Many factors related to family life have been shown to influence addictive behavior, including stress; observance of domestic violence between family members; experience of abuse by a parent, sibling, or other relative; isolation; genetics; and the existence of alcoholism in the family. These factors might be specific and obvious or ill-defined and subtle. Often it is difficult to identify a problem and facilitate assistance for an individual because of denial among family members.

A. Role of Genetics

Certain factors are unchangeable and therefore are not focused on when attempting to create services or educational programs for alcohol addiction. However, it is important to acknowledge and understand the role of these factors to fully appreciate the possible components at work in addiction development.

An individual's genes can determine the possible effects of alcohol, and further, the possibility of developing alcohol addiction. Genes can determine how an individual's body metabolizes alcohol. The slower alcohol is metabolized, the quicker the effects of the alcohol can be experienced and vice versa (International Center for Alcohol Policies, 2001). Furthermore, genes can affect an individual's alcohol tolerance, ability to process the alcohol, and risk of alcoholism or alcohol addiction.

Enzymes called alcohol dehydrogenase (ADH) and aldehyde dehydrogenase (ALDH) are found in the liver and help the alcohol eventually metabolize into carbon dioxide and water. In people with certain genotypes, these enzymes are less active or less efficient; these gene variants can be more prevalent in certain populations (e.g., some Asian ethnicities) (International Center for Alcohol Policies, 2001). People with deficiencies of ADH and ALDH might be more susceptible to the effects of alcohol.

Genes linked with alcohol tolerance and dependence are typically inherited. One study suggests that an estimated 5%–10% of females and 25% of males who have relatives who are alcoholics will develop alcohol dependence themselves. This study suggests that alcoholism can be passed down from generation to generation. It also suggests that (depending on an individual's genes) males and females can experience the effects of alcohol differently. It is important to note, however, that genetics are but one of the factors that can determine an individual's risk of alcoholism. Many other factors contribute to the development of alcohol dependence (International Center for Alcohol Policies, 2001).

B. Family Factors That Might Contribute to Alcohol Use

A parent's consumption of alcohol is thought to be associated with a child's initiation and continuation of alcohol consumption. A study on heritability and alcoholism found that "early use of alcohol in mothers...was associated with a significant increase in both sons' and daughters' risk of alcohol use by age 14" (McGue, Iacano, Legrand, & Elkins, 2001, p. 1166).

Maternal alcohol consumption and behavior can increase the risk of alcohol use by her children. Alcoholism in a parent can cause negative social and emotional consequences that last into adulthood and can increase the risk of alcohol misuse (Table 3.9).

Parental attitudes about drinking alcohol are also associated with whether a child will initiate and continue to drink. "Children who were warned [of the negative effects of] alcohol by their parents and children who reported being closer to their parents were less likely to start drinking" (NIAAA, 1997).

One study showed that higher levels of emotional abuse, parental alcoholism, constant parental conflict, and being made to feel unwanted or unloved can lead to alcohol addiction. The women in the study, who were recovering alcoholics, experienced more aversive childhood experiences than the general population (Harmer, Sanderson, & Mertin, 1999).

A parent's or caregiver's lack of involvement or negative involvement in a child's life (especially in the formative years) can also lead to alcoholism. A lack of involvement can include lack of support, monitoring, and communication; negative involvement includes harsh, inconsistent discipline, and hostility or rejection. It is important to note that not only direct and obvious abuse, such as physical and sexual abuse, is included here. A child's feeling neglected by his or her parent because of insufficient attention is also a risk factor for alcoholism (NIAAA, 1997).

Family atmosphere can affect the age at which an individual will initiate alcohol consumption. The earlier the initiation of alcohol use, the more likely that individual will develop an abusive relationship with alcohol (Kosterman, Hawkins, Guo, Catalano, & Abbott, 2000). In addition, teens whose families provide them with strong social support are less likely to use alcohol, according to one study (Mason & Windle, 2001).

Table 3.9. The 13 Characteristics of Adult Children of Alcoholics

Adult children of alcoholics

1. Guess at what normal behavior is.
2. Have difficulty following a project through from beginning to end.
3. Lie when it would be just as easy to tell the truth.
4. Judge themselves without mercy.
5. Have difficulty having fun.
6. Take themselves very seriously.
7. Have difficulty with intimate relationships.
8. Overreact to changes over which they have no control.
9. Constantly seek approval and affirmation.
10. Usually feel that they are different from other people.
11. Are super responsible or super irresponsible.
12. Are extremely loyal, even in the face of evidence that the loyalty is undeserved.
13. Are impulsive. They tend to lock themselves into a course of action without giving serious consideration to alternative behaviors or possible consequences. This impulsivity leads to confusion, self-loathing, and loss of control over their environment. In addition, they spend an excessive amount of energy cleaning up the mess.

Source: Woititz, J.G. (1990). *The 13 characteristics of adult children*. Retrieved August 17, 2007, from http://www.drjan.com/13char.html.

Suggested Learning Activities

- Lead a group discussion about alcoholism and related characteristics.
- Set up a debate on similarities and differences of various categories of alcohol use.
- Use a case study of a woman that illustrates the addictive disease process.
- Have small groups generate a list of questions for screening of alcohol use and determining need for referral.
- Create an activity matching drinking descriptions to types of drinks.
- Use mini-case studies or scenarios of women for group discussion of types of drinkers.
- Have groups develop real-life cases/scenarios for the various components of alcohol use.
- Use case studies or short scenarios of women in various stages of change to highlight differences among stages.
- Ask learners to work individually or in small groups on an activity designed to illustrate stages of change. Have each individual work on a situation and identify the various stages of addressing a problem. Have them relate it to an alcohol-related scenario.
- Use case studies of women in various stages of change and have the group select what stage each woman is in and give a rationale for the selection.
- Use case studies that illustrate various psychiatric co-morbidities.
- Discuss when and to whom to refer women exhibiting co-morbidities.
- Discuss how alcohol use and dependency interrelate with family and other relationships.

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Learning Goals and Related Objectives

Goal III-A: Explain past and current models of alcohol abuse

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe some of the historical alcohol use models. (K) ▪ Describe alcohol use based on various models. (S)	▪ Identify various models used historically (moral, sociocultural, psychological, addictive disease, biomedical). (K) ▪ Identify cultural biases in the use of various models. (K) ▪ Implement knowledge of models in current practice. (S)	▪ Explain to other health professionals the limitations of historical models of alcohol dependency. (K)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal III-B: Describe the categories of alcohol use in women

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe different types of drinkers (abstainers, low-risk drinkers, at-risk drinkers, problem drinkers, alcohol-dependent drinkers). (K) ▪ Explain how to assess women for different categories of alcohol use. (K) ▪ Identify accurately the categories of alcohol use. (S) ▪ Demonstrate the ability to ask appropriate questions pertaining to alcohol use in pregnant women to categorize types of drinkers. (S) ▪ Effectively categorize women according to their drinking patterns. (S)	▪ Explain how categories of alcohol use might change throughout pregnancy. (K) ▪ Demonstrate in-depth knowledge of five patterns of alcohol consumption in pregnant women (from no consumption of alcohol at all to the inability to stop drinking once started). (K) ▪ Explain the concept of underreporting of alcohol use and how it varies across individuals. (K) ▪ Conduct comprehensive interviews to classify types of drinkers and patterns of alcohol use. (S)	▪ Analyze new research and information, which will further develop the ability to secure needed information about drinking patterns. (K) ▪ Explain in depth the most current theories of addiction. (K) ▪ Demonstrate to other practitioners how to use appropriate questions that identify types of drinking patterns. (S) ▪ Demonstrate how to ask questions in a matter-of-fact, nonjudgmental, and empathic way. (S) ▪ Advise other health care professionals on how to overcome possible barriers during interviews. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal III-C: Describe stages of alcohol use, dependence, and addiction

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe how increased alcohol use might lead to physical, psychological, and lifestyle changes. (A) ▪ Identify features of physical, psychological, and lifestyle changes indicative of increased alcohol use. (K) ▪ Describe the most current medical criteria for alcohol use disorders. (K) ▪ Use most current nomenclature for identifying stages of alcohol misuse. (S)	▪ Explain how issues such as tolerance and dependency are part of the progression of alcoholism. (A) ▪ Explain how individuals from different cultures and economic backgrounds might view alcohol use differently, with varying levels of tolerance. (A) ▪ Describe specific physical, psychological, and lifestyle changes indicative of increased alcohol use. (K) ▪ Explain the methods of eliciting information and criteria for alcohol use disorders. (K) ▪ Use current gender-specific assessment tools that are successful in identifying problem use and need for further intervention. (S) ▪ Use the current medical criteria when evaluating patients. (S)	▪ Explain to other health professionals the progression of alcoholism. (K) ▪ Explain to others how gender- and culture-specific intervention and counseling techniques are used with women in different stages of addiction. (S) ▪ Review and assess new research to classify and describe stages of alcoholism in pregnancy. (S) ▪ Explain to other health professionals about symptoms of addictive disease process. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal III-D: Explain the stages of change in alcohol use

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Explain why an alcoholic woman will need treatment to stop use during pregnancy. (K) ▪ Describe the stages of change in alcohol use (pre-contemplation, contemplation, preparation, action, maintenance). (K) ▪ Identify brief interventions that will assist with change. (K) ▪ Explain how to interview women in a nonjudgmental way to promote self-assessment and change. (S) ▪ Provide information on the benefits of decreasing or stopping alcohol use for mother and baby. (S)	▪ Describe how underreporting is part of the denial that manifests in alcoholism. (A) ▪ Identify specific information related to each stage of change. (K) ▪ Describe potential barriers to change in alcohol use among women, including cultural beliefs. (K) ▪ Use flexible interviews to identify stages of change. (S) ▪ Direct pregnant women who drink into appropriate treatment setting and monitor treatment progress. (S)	▪ Explain to other practitioners the concept and use of stages of change with pregnant women who drink alcohol. (K) ▪ Identify community resources that can assist in enabling change, understanding that there are treatment beds for pregnant women and their children. (K) ▪ Review and assess literature for effective community treatments. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal III-E: Address co-occurring psychiatric disorders related to alcohol use

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Explain how certain disease processes can affect alcohol use. (A) ▪ Explain how psychological disorders are associated with problematic alcohol use. (A) ▪ Identify specific psychological disorders that are associated with increased alcohol use (e.g., depression, ADHD, mood disorders, PTSD, impulse control problems, FASDs). (K) ▪ Demonstrate a clear understanding of the addictive disease process and how that might mimic a psychological disorder. (S) ▪ Explain the interplay of alcohol use and unaddressed co-morbid issues. (S)	▪ Explain how many psychiatric disorders are associated with increased alcohol use or dependence (e.g., ADHD, depression, bipolar disorders, PTSD, impulse control problems, anxiety, eating disorders, FASDs). (A) ▪ Explain how one's own comfort level can assist in obtaining necessary information about co-morbidities. (A) ▪ Describe how alcoholic patients are frequently misdiagnosed with psychiatric disorders without an associated diagnosis of alcoholism. (K) ▪ Recognize that a clinical assessment might be necessary to obtain an accurate assessment of the addictive disease process with or without a co-morbid disorder. (K) ▪ Direct questions during an interview to obtain information on co-morbidity and drinking use. (S) ▪ Demonstrate the ability to refer patients who need specific psychiatric intervention to appropriate specialist. (S)	▪ Summarize current research regarding identification and treatment of co-morbid issues. (K) ▪ Explain to other practitioners the possible co-morbid issues in alcohol dependence to assist in their practice. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal III-F: Recognize characteristics of alcohol-dependent families

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Explain the role that genetics play in determining individuals at risk for alcoholism. (A) ▪ Explain how certain characteristics in families might contribute to alcohol use and dependency. (A) ▪ Identify some family factors that might contribute to alcohol use (e.g., genetics, stress, isolation, low self-esteem, alcoholism in families). (K) ▪ Recognize reciprocity in the relationship between an individual and his or her family (i.e., individual both affects and is affected by family factors/processes). (K) ▪ Demonstrate ability to ask open-ended questions to promote discussion and reflection of family issues. (S) ▪ Identify families at risk for possible alcohol dependency. (S)	▪ Describe how different family characteristics contribute to alcohol use and dependency in families. (A) ▪ Demonstrate the ability to be nonjudgmental and empathic with alcohol-dependent families. (A) ▪ Identify specific and subtle family factors that contribute to a woman's risk for alcohol use and alcoholism. (K) ▪ Describe the role of denial in alcohol-dependent families. (K) ▪ Anticipate that interventions directed at individuals will also potentially impact families and that interventions directed at families will impact individuals. (K) ▪ Evaluate risk factors for alcohol dependency in families. (S) ▪ Assess family dynamics for possible alcohol dependency. (S) ▪ Support women in clarifying how family dynamics affects their drinking. (S)	▪ Describe to other health professionals about family and cultural factors in alcohol use and dependency. (A) ▪ Demonstrate successful family interventions to other health professionals. (S) ▪ Promote important community support systems for families (e.g., counseling, alcohol treatment). (S) ▪ Evaluate literature for new family therapies for alcohol-dependent families. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Competency IV: Biological Effects of Alcohol on Fetus

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

Learning Goals

(Learning objectives for each goal can be found at the end of this section.)

IV-A Define the amount of alcohol in a drink.

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

IV-C Describe birth defects associated with alcohol use.

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

IV-E Describe cellular responses to alcohol exposure.

IV-F Explain putative biomedical mechanisms.

IV-G Explain the effects of ethanol exposure on neurobehavioral outcomes, specifically those that are cognitive and psychiatric/behavioral.

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

Content Outline for Competency IV

I. **Defining amount of alcohol in a drink**
   A. Volume
   B. Quantity of alcohol

II. **Alcohol metabolism and pharmacology**
   A. Absorption
   B. Distribution
   C. Metabolism and elimination

III. **Neuromorphological birth defects associated with alcohol use**
   A. FAS
   B. FASDs

IV. **Alcohol-induced injuries on developing nervous system**
   A. Sensitivity throughout gestation
   B. Postnatal effects of alcohol abuse

V. **Cellular response to alcohol exposure**
   A. Neurogenesis
   B. Growth and differentiation of neurons
   C. Migration
   D. Synaptogenesis
   E. Apoptosis
   F. Plasticity

VI. **Putative biomedical mechanisms**
   A. Neuromorphological and neurotrophic effects
   B. Effects on neurotransmitter receptors
   C. Effects on signal transduction

VII. **Fetal alcohol exposure effects on neurobehavior**
   A. Cognitive
   B. Psychiatric/behavioral

VIII. **Genetic variants and markers**

Also included in this section are:

- Suggested learning activities.
- References.
- Chart of all learning goals and objectives for this competency.

I. Defining Amount of Alcohol in a Drink

Kevin Rudeen, PhD

A clear understanding of the quantity of alcohol consumed is important in assessing risk. Determining the amount of alcohol exposure can be difficult, however, because of cultural and societal differences in what constitutes a "drink." The molecular nature of alcohol (ethyl alcohol) allows for the molecule to be readily solubilized into aqueous solutions in various concentrations and volumes (National Institute on Alcohol Abuse and Alcoholism [NIAAA], 2005). Given this variety, responses to a general question inquiring about "drinks consumed" might yield imprecise information about the total amount of alcohol consumed in a drinking session or by a person at risk for alcoholism.

A. Volume

To evaluate a rough equivalency of alcoholic beverages, it is important to consider the concentration of alcohol used in the beverage as well as the volume. For example, NIAAA guidelines (2005) use the following beverage types and volumes as rough equivalencies for standard drinks:

- One 12-ounce (355 ml) can or bottle of beer
- One 5-ounce glass of wine
- One 12-ounce wine cooler
- One 4-ounce glass of sherry, liqueur or aperitif
- One "shot" of liquor (distilled alcohol), 1.5 ounces

B. Quantity of Alcohol

The quantity of alcohol in each of the above drinks is approximately equal. This is easily determined by estimating the percent alcohol used in the drink (e.g., beer = 3%–5% by volume). Simple calculations indicate that one can of beer contains approximately 11 ml of alcohol (355 ml x 0.03), and within the 11 ml there is approximately 8.7 g of alcohol (11 ml x 0.789 g/ml). Each of the above drinks contains 8–10 grams of alcohol (roughly). The exception is the "shot" of spirits. While 1–1.5 ounces is commonly used in a "mixed drink," the percent alcohol contained within the shot is variable with some spirits being 30% alcohol, and others spirits being 80% or more. Although the high end of 10 grams of alcohol in one mixed drink would be a reasonable estimate, one must be aware that it could be greater depending on the spirits used in the drink.

II. Alcohol Metabolism and Pharmacology

Kevin Rudeen, PhD

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

A. Absorption

When a woman takes a drink, the ethanol in that drink is introduced into the stomach where absorption (and metabolism) of the molecule (C_2H_5OH) occurs rapidly. The absorption rate might be influenced by other contents in the stomach; it is most rapidly absorbed from an empty stomach. Peak blood ethanol concentrations are attained approximately 1 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.).

It has been demonstrated that, given the same amount of alcohol under standardized conditions, women attain consistently greater blood ethanol concentrations than men following equivalent amounts of ethanol consumption (NIAAA, 1999). This fact 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 do men. This fact is important given its significance to the embryo or fetus if the woman were pregnant.

B. Distribution

1. **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, most apparent, the nervous system (brain, spinal cord, and peripheral nerves).

2. **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 therefore, acts as a selective barrier. Unfortunately, the placenta 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 compartments much as occurs 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 & Raiha, 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. Alcohol is metabolized by the enzymes as it is available by 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 (Greenfield, 2001; 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). The hepatocytes of the liver contain three pathways for ethanol metabolism:

- The alcohol dehydrogenase (ADH) pathway in the cytosol (primary) pathway.
- The microsomal ethanol oxidizing system (MEOS) pathway—enzymes located in the smooth endoplasmic reticulum of the hepatocyte (and other cells).
- The catalase pathway (peroxisomal) located in the hepatocytes and other cells.

Metabolism occurs primarily through the ADH pathway. Chronic ethanol exposure might enhance or induce other pathways. Specifically, chronic alcohol exposure could enhance the MEOS system to account for as much as up to 10% of the ethanol oxidation.

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 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 performed in animals and humans to attempt 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 hepatocyte performs most of the alcohol metabolism through the 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 occurs by simple diffusion to the mother, during the metabolism phase, embryonic alcohol levels might be higher than in the mother and be present for a more prolonged, but variable time. The prolongation of the alcohol concentration and the time that exposure might occur could be significant to the developing embryo or fetus.

III. Neuromorphological Birth Defects Associated With Alcohol Use

Kevin Rudeen, PhD

A. FAS

To describe the neuromorphological birth defects associated with 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 detectible by magnetic resonance imaging (MRI) or sonography (Bookstein, Sampson, Connor, & Streissguth, 2002).

An animal study has shown that the craniofacial malformations associated with FAS might be explained by embryological changes that occur in development of the brain and the facial structures. Indeed, exposure of mice to alcohol during development resulted in features similar to FAS in humans (e.g., microcephaly and a reduced head circumference, smaller palpebral fissures, and the reduction of the philtrum and upper lip structures) (Sulik & Johnston, 1983).

B. FASDs

Fetal alcohol spectrum disorders (FASDs) is a term referring to individuals who have more than one of the features associated with FAS but do not exhibit sufficient features to make a clear FAS diagnosis. Included within this terminology is alcohol-related neurodevelopmental disorder (ARND).

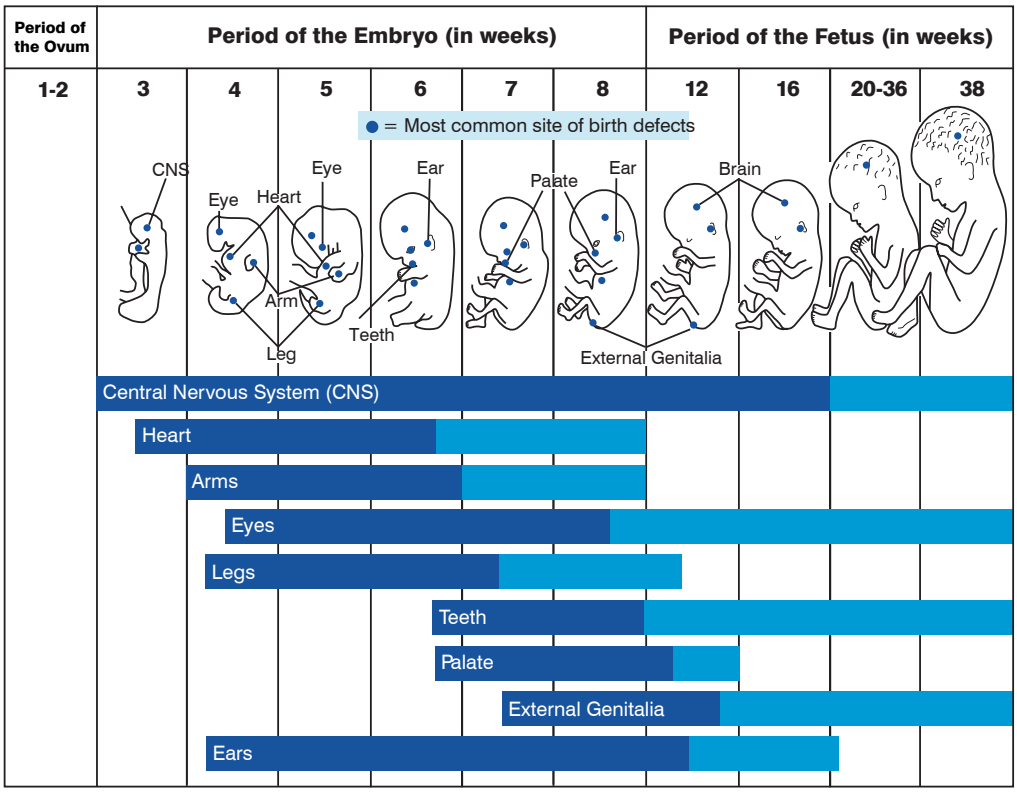
It is important to note that FASDs is a term that includes children who have been exposed to alcohol during fetal development. Although they might not have craniofacial effects of FAS, they will have secondary behavioral and cognitive effects resulting from the alcohol exposure.

IV. Alcohol-Induced Injuries on Developing Nervous System

Kevin Rudeen, PhD

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



Vulnerability of the fetus to defects during different periods of development. The dark blue portion of the bars represents the most sensitive periods of development, during which teratogenic effects on the sites listed would result in major structural abnormalities in the child. The lighter blue portion of the bars represents periods of development during which physiological defects and minor structural abnormalities would occur.

Source: National Organization on Fetal Alcohol Syndrome (NOFAS), 2004; Adapted from Moore, 1993.

A. Sensitivity Throughout Gestation

Development of the nervous system begins in about the 3rd week of gestation and continues throughout gestation.

An estimated 95–100 billion neurons are found in the human cortex (Pakkenberg & Gundersen, 1997), making the rate of generation nearly 250,000 new neurons formed each minute of the 9-month gestational period in the cortex alone. That calculation assumes a continuous rate of generation over the 40-week period. However, studies have shown that the nervous system develops in a discontinuous manner with periods of greater developmental activity followed by periods of relative quiescence in development. 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, such as spontaneous abortion. 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 FASDs and those with FAS (Hunt, Streissguth, Kerr, & Olson, 1995; Janzen, Nanson, & Block, 1995; Mattson et al., 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). Undoubtedly, 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—might be as damaging as drinking that occurs more chronically (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.

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 gross motor movements.

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.

V. Cellular Response to Alcohol Exposure

Kevin Rudeen, PhD

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 (Gemma, Minana, 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 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 (Gemma 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, & Gure, 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, but when maturation occurs, they are regarded as post-mitotically static, and they 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).

VI. Putative Biomedical Mechanisms

Kevin Rudeen, PhD

Numerous scientific studies have sought to determine the biomedical mechanisms associated with FAS and 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. These 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.
- Alters prostaglandin levels.
- Impairs DNA methylation, resulting in alteration of transcription in preparation for RNA expression.
- Alters mRNA translation of protein synthesis.
- Disorders fluidity and organization of the membrane phospholipid bilayer.
- 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.

C. Effects on Signal Transduction

Some investigations have focused on specific transduction events within cells in response to stimulation that might be affected by fetal alcohol exposure (Perrone-Bizzozero, Keidan, Eriqat, Savage, & Allan, 1998). Effects include:

- Altered G-protein transduction systems.
- Reduction of adenylate cyclase activity.
- Increased protein kinase C phosphorylation.
- Increased release of calcium into the cytosol.
- Up-regulation of voltage-gated calcium channels.

Pharmacologically, ethanol is a "dirty" drug. Although classified as a depressant, it might have a variety of molecular effects, rather than one specific effect. FAS 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 FAS or FASDs. Rather, it is more likely that FAS or FASDs is a result of the additive or synergistic effects of alcohol on the developing system.

VII. Fetal Alcohol Exposure Effects on Neurobehavior

Kevin Rudeen, PhD

A. Cognitive

As discussed in previous sections, alcohol exposure is associated with a variety of potential structural and functional alterations to the developing nervous system (Goodlett & Horn, 2001). Any single alteration affects the ability of the cell to function appropriately and correctly communicate or process information essential to the nervous system. Reduced function or efficiency of nerve cells will result in alterations that might be expressed as changes in functions related to thinking, learning, and movement. However severe or subtle they might be, the effects of alcohol might contribute to intellectual disability or movement disorders as part of the organic disturbance to the formation and function of the brain and its cellular components. One study found that the average IQ of 178 individuals diagnosed with FAS was 79 (range 20–120) (Streissguth et al., 1996), which is below the general population range of 85–115.

B. Psychiatric/Behavioral

Also associated with organic brain dysfunction are various maladaptive behaviors and symptoms of people with FAS and other FASDs. Behavioral deficits might include attention deficits, memory problems, and hyperactivity. Less common are a lack of awareness of what is happening in one's immediate surroundings, peculiar mannerisms or habits, preoccupations, or self-injurious behavior.

Memory and learning impairments are common features of FAS and FASDs, although the specific deficits experienced by individuals with these conditions vary widely (Mattson et al., 1996; Roebuck, Mattson, & Riley, 1999). Some investigators have linked these deficits to alterations in brain structure, at least for those impairments that might be ascribed to an area or areas of the brain related to that respective function (e.g., language) (Mattson et al., 1996; Roebuck et al., 1999).

Verbal learning. Children exposed to alcohol prenatally exhibit a variety of problems with language and memory (Mattson et al., 1996). Children ages 5 to 16 with FAS learned fewer words than a group of children of comparable mental age who did not have FAS, but recall was not impaired in children with FAS. These findings indicate that FAS-related learning problems occur during the initial stages of memory formation (i.e., encoding).

Visual-spatial learning. Children with FAS perform poorly on tasks that involve learning spatial relationships among objects. For example, children with FAS had greater difficulty than children without alcohol exposure in returning common kitchen objects to their original positions on a table (Hunt et al., 1995; Uecker & Nadel, 1996).

Attention. Attention problems are a hallmark of prenatal alcohol exposure. Children exposed to alcohol prenatally are able to focus and maintain attention, but they display difficulty in *shifting* attention from one task to another (i.e., set shifting) (Coles et al., 1997).

Reaction time. How quickly the brain processes information is part of individual differences in intelligence measures. Exposure to alcohol during pregnancy has been associated with slower,

less efficient information processing, as measured by longer reaction times in both school-age children and infants (Jacobson, Jacobson, & Sokol, 1994).

Executive functions. Executive functions are activities that require abstract thinking, such as planning and organizing. Children exposed to alcohol prenatally respond poorly when asked to switch back and forth from identifying classes of objects (e.g., animals versus types of furniture). Children with FAS also have difficulty abandoning ineffective strategies when approaching problem-solving tasks. Children with FAS are easily distracted and impulsive, factors that might contribute, at least theoretically, to attention and learning problems (Janzen et al., 1995; Kodituwakku, Handmaker, Cutler, Weathersby, & Handmaker, 1995; Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998).

These behaviors might be expressed through secondary disabilities, six of which have been recognized and assessed (Stratton et al., 1996; Streissguth et al., 1986; 1996): (a) mental health problems, (b) disrupted school experiences, (c) trouble with the law, (d) confinement and/or incarceration, (e) inappropriate sexual behavior, and (f) alcohol or other drug problems.

See Competency V for more information about fetal alcohol exposure effects on neurobehavior.

VIII. Genetic Variants and Markers

Kevin Rudeen, PhD

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 tended 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 unknown whether or not this polymorphism will help predict which specific alcohol-consuming women are at higher risk of having a child with an FASD.

Suggested Learning Activities

- Have a series of glasses (or paper representatives) for the group to identify a standard drink. Expand to relate to at-risk drinkers.
- Use standard drink chart in ACOG Tool Kit (http://www.acog.org/departments/healthIssues/StandardDrinkCard.pdf
- Ask the group to draw out what happens when a drink is ingested by a pregnant woman.
- 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.

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Learning Goals and Related Objectives

Goal IV-A: Define the amount of alcohol in a drink

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Define what constitutes a "drink" based on the alcoholic quantity and volume of a beverage. (K)	▪ Explain clearly to a patient or to other health care workers the equivalencies of drinks based on the alcoholic quantity and volume of a beverage. (S)	▪ Demonstrate to other health professionals in how to explain to a patient what constitutes a "drink." (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal IV-B: Explain alcohol metabolism and pharmacology (absorption, distribution, metabolism, and elimination)

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Explain how alcohol is transferred to the fetus via the placenta. (K) ▪ Describe the process of ethanol absorption, its distribution among body compartments and tissues, its metabolic kinetics, and the process of elimination. (K) ▪ Describe the differences between genders in ethanol pharmacokinetics. (K)	▪ Describe the process of ethanol pharmacokinetics. (K) ▪ Describe the metabolism of alcohol in the fetus. (K) ▪ Explain the process of ethanol absorption, distribution among body compartments and tissues, its metabolic kinetics, and process of elimination. (K)	▪ Explain to other health professionals the process of ethanol absorption, distribution among body compartments and tissues, its metabolic kinetics, and process of elimination. (S) ▪ Explain to other health professionals, in appropriate detail, the process of ethanol pharmacokinetics, including the process of ethanol absorption, distribution among body compartments and tissues. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal IV-C: Describe birth defects associated with alcohol use

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Identify birth defects associated with alcohol use and FASDs. (K)	▪ Identify birth defects that can result from prenatal alcohol use that are associated with FASDs. (K) ▪ Describe to a patient, family member, or caregiver the constellation of features comprising FASDs. (S)	▪ Explain to other health professionals the range of birth defects that can result from prenatal alcohol exposure. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal IV-D: Describe alcohol-induced injuries on the developing nervous system

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Identify effects of maternal alcohol exposure on the developing nervous system during each trimester. (K) ▪ Describe the postnatal effects of alcohol exposure through breastfeeding. (K) ▪ Describe in general terms the effects of alcohol on cellular growth and differentiation. (K)	▪ Explain to a patient the effects of alcohol exposure on the developing nervous system during each trimester. (S) ▪ Explain to a patient the postnatal effects of alcohol from breastfeeding. (S)	▪ Explain in appropriate detail to other health professionals the predictable alcohol-induced injuries that might result from exposure during each trimester. (S) ▪ Explain to other health professionals the process by which alcohol might affect the newborn through breastfeeding. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal IV-E: Describe cellular responses to alcohol exposure

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Explain how alcohol affects cellular "birth," growth, and differentiation. (K) ▪ Explain how alcohol alters migration and apoptosis of cells in the formation of organs during the developmental period. (K) ▪ Identify how alcohol exposure during brain development will interfere with development of the nervous system. (K)	▪ Explain how alcohol exposure affects cellular "birth," growth, and differentiation and migration in formation of organs in the fetus. (K) ▪ Describe how alcohol exposure might influence cell apoptosis during fetal development. (K) ▪ Describe in general how alcohol might influence the development of neurons and their ability to form centers (nuclei) or connections with one another. (K) ▪ Summarize briefly to a patient the effects of alcohol on neurogenesis and the effects of alcohol on cellular migration. (S)	▪ Explain to other health professionals, in general terms, some of the cellular responses to alcohol exposure. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal IV-F: Explain putative biomedical mechanisms

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ State briefly the neuromorphological and neurotropic effects of alcohol. (K) ▪ State briefly the effects of alcohol on neurotransmitter receptors. (K) ▪ State briefly the effects of alcohol on signal transduction. (K)	▪ Describe the neuromorphological effects and neurotropic effects of alcohol. (K) ▪ Describe the effects of alcohol on neurotransmitter receptors. (K) ▪ Describe the effects of alcohol on signal transduction. (K)	▪ Describe to other health professionals about the key points of studies conducted to determine the biomedical mechanisms associated with FAS and other prenatal alcohol-related disorders. (K)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal IV-G: Explain the effects of ethanol exposure on neurobehavioral outcomes, specifically those that are cognitive and psychiatric/behavioral

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe the effects of alcohol on cognitive function. (K) ▪ Describe the effects of alcohol on behavior. (K)	▪ Explain to a patient or caregiver how alcohol exposure alters cognitive function and might result in behavioral alterations. (S) ▪ Explain to a patient or caregiver how structural and functional changes due to alcohol exposure will result in neuromorphological and/or behavioral alterations. (S)	▪ Describe to other health professionals the effects of ethanol on cognitive function. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal IV-H: Describe genetic variants and markers for susceptibility for FAS

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Summarize briefly the differences in ethanol metabolism due to genetic variations. (K) ▪ Identify genetic markers associated with risks and susceptibility for FASDs. (K)	▪ Summarize generally to a patient how genetic markers might be important in determining the risks and susceptibility for FASDs. (S)	▪ Describe to other health professionals examples of how genetic markers might provide understanding for future determination of susceptibility to FASDs in individuals. (S) ▪ Describe to other health professionals a specific explanation of the differences in alcohol metabolism due to genetic variations. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Competency V: Screening, Diagnosis, and Assessment of FAS

The health care student or provider will be able to screen, diagnose, and assess infants, children, adolescents, and adults for FAS and other prenatal alcohol-related disorders.

Learning Goals

(Learning objectives for each goal can be found at the end of this section.)

V-A Describe the "Framework for FAS Diagnosis and Services."
V-B Explain the diagnostic criteria for FAS.
V-C Understand appropriate criteria for referral for an FAS diagnostic evaluation.
V-D Understand the assessment, evaluation, and feedback process.

Content Outline for Competency V

I. **Framework for FAS diagnosis and services**
   A. Initial identification
   B. Referral
   C. Diagnosis

II. **FAS diagnostic criteria**
   A. Presence of facial dysmorphia
   B. Growth problems
   C. Central nervous system abnormalities
   D. Maternal alcohol exposure
   E. Need for criteria for other alcohol-related disorders

III. **Considerations for a referral for an FAS diagnostic evaluation**

IV. **Evaluation of fetal alcohol spectrum disorders**
   A. Characteristics of fetal alcohol spectrum disorders
   B. Overview of the assessment process
   C. Components of the evaluation
   D. Feedback process

Also included in this section are:

- Suggested learning activities.
- References.
- Chart of all learning goals and objectives for this competency.

I. Framework for FAS Diagnosis and Services

This section is adapted from Bertrand, J., Floyd, R. L., Weber, M. K., O'Connor, M., Riley, E. P., Johnson, K. A., Cohen, D. E., & National Task Force on FAS/FAE. Fetal alcohol syndrome: Guidelines for referral and diagnosis. Atlanta, GA: Centers for Disease Control and Prevention; 2004.

In 2004, through coordinated efforts of the Centers for Disease Control and Prevention, the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, and a scientific working group of experts in FAS research, diagnosis, and treatment, the CDC Fetal Alcohol Syndrome Guidelines for Referral and Diagnosis were published.

The framework in Figure 5.1 provides an overview of the entire identification, referral, diagnosis, and treatment process. This overview guided the scientific working group in identifying key points that needed to be addressed to develop specific guidelines for referral and diagnosis of FAS. The framework also reflects CDC's recommendation that developmental screening be implemented to improve children's health and help them reach their full potential. A discussion of the major points of the framework follows.

A. Initial identification

Initial recognition that a child or older individual has a potential problem can come from many sources. Often, parents notice differences between a child and his or her siblings. School systems, including Head Start and daycare staff, interact with a large number of children and often recognize when someone is having difficulty. Social service professionals, such as Women, Infants, and Children (WIC) clinic staff, social workers, and foster care agencies, frequently recognize children and individuals having difficulty and needing evaluation. And finally, health care providers (particularly pediatricians) often are the first to screen for and detect problems; or obstetricians, who might be aware of a maternal substance abuse problem, might refer a newborn. Recognition of many of the problems associated with FAS is exactly the type of condition the "well child" visits to the doctor's office are meant to identify. It is assumed that triggers, such as facial abnormalities, growth delay, developmental problems, or maternal alcohol use, will emerge from the contact. Recognition of a potential problem should lead the provider, regardless of specific profession, to facilitate getting the child and his or her family to the appropriate next step.

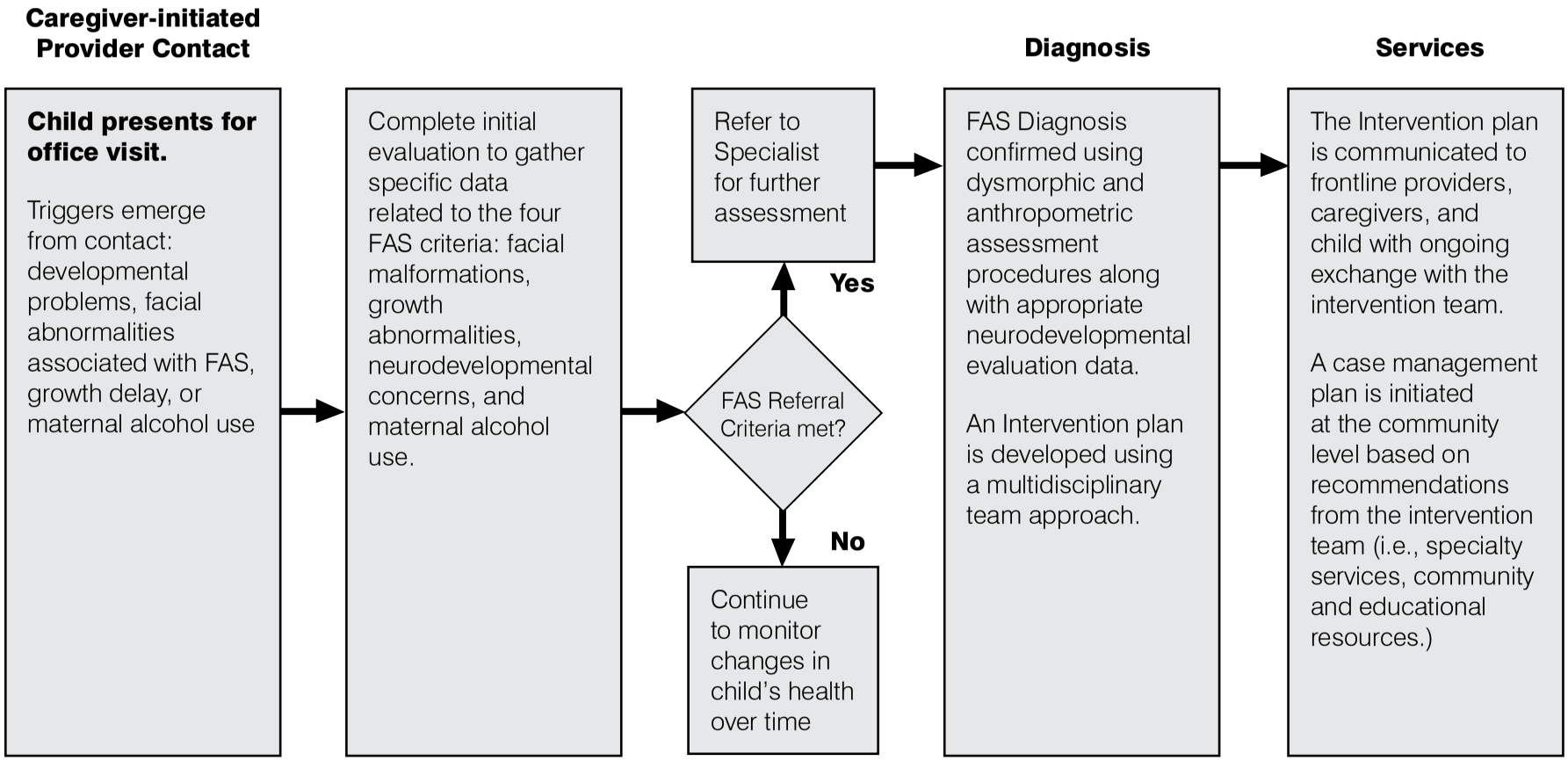
B. Referral

The referral process is initiated at the point a clinician starts to suspect an alcohol-related disorder for a child. This process is facilitated by thorough knowledge of the physical and neurodevelopmental domains affected in individuals with FAS, as well as characteristics that could trigger a referral. In making a referral for a complete diagnostic evaluation for FAS, it is helpful for the referring provider to gather and document specific data related to the FAS criteria. These data will assist the provider in making the decision to diagnose the child or to refer the child to a multidisciplinary evaluation team for a confirmed diagnosis. In addition, these data could be forwarded to the multidisciplinary evaluation team to guide the diagnostic process. A complete review of systems, noting features consistent with FAS, will be most productive.

C. Diagnosis

Typically, a multidisciplinary team thoroughly assesses the child using FAS diagnostic procedures to evaluate dysmorphia (abnormality of shape or form) and growth parameters and to obtain appropriate neurodevelopmental evaluation data. Once a diagnosis is made, an intervention plan is developed using a multidisciplinary team approach. A variety of specialists could contribute to the multidisciplinary team, including dysmorphologists, developmental pediatricians, psychiatrists, psychologists, social workers, and educational specialists. Other clinicians, such as pediatricians and family practitioners, also might make the FAS diagnosis, with appropriate training in the use of these guidelines. In many rural and less populous regions, these clinicians must make the diagnosis for many types of birth defects and developmental disabilities. Many of these evaluation services are available within the community; for example, school systems could provide neurocognitive assessments.

Figure 5.1. Framework for FAS Diagnosis and Services



Source: Bertrand J, Floyd RL, Weber MK, O'Connor M, Riley EP, Johnson KA, Cohen DE, National Task Force on FAS/FAE. Fetal alcohol syndrome: Guidelines for referral and diagnosis. Atlanta, GA: Centers for Disease Control and Prevention; 2004, p. 8.

II. FAS Diagnostic Criteria

This section is adapted from Bertrand, J., Floyd, R. L., Weber, M. K., O'Connor, M., Riley, E. P., Johnson, K. A., Cohen, D. E., & National Task Force on FAS/FAE. Fetal alcohol syndrome: Guidelines for referral and diagnosis. Atlanta, GA: Centers for Disease Control and Prevention; 2004.

Clear diagnostic criteria for FAS, and instructions on their use, can help health care providers better identify children with this condition. With the diagnosis of FAS, children can begin to get the care and services they need. Early identification of the condition can help to prevent serious secondary conditions that often result if diagnosis is delayed.

The diagnosis of FAS requires all three of the following:

1. Documentation of all three facial abnormalities (smooth philtrum, thin vermillion, and small palpebral fissures).
2. Documentation of growth deficits.
3. Documentation of CNS abnormality.

These criteria are discussed in detail in this section.

A. Presence of Facial Dysmorphia

The effects of alcohol on the developing fetus depend on the timing, amount, and frequency of alcohol consumption by the mother. Drinking alcohol early in pregnancy may result in facial anomalies since this is a critical period when organs such as the brain and eyes are forming. While individuals with FAS often present with a variety of physical malformations or dysmorphic features, the clinical features most often identified have been facial anomalies. According to the 2004 FAS Guidelines, an individual needs to exhibit all three characteristic facial features (based on racial norms):

- Smooth philtrum (University of Washington Lip-Philtrum Guide – ranking of 4 or 5)
- Thin vermillion (University of Washington Lip-Philtrum Guide – ranking of 4 or 5)
- Small palpebral fissures (at or below 10th percentile based on age and racial norms)

These three features are not unique to FAS; thus, the process of differential diagnosis is essential in making an accurate FAS diagnosis. For more information about differential diagnosis, refer to *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis* (2004).

Lip-philtrum guide. The Lip-Philtrum Guide is a 5-point pictorial ruler that measures the thinness of the upper lip and smoothness of the philtrum. A "1" on the scale depicts a thick upper lip and deeply-grooved philtrum; a "5" depicts the thin upper lip and smooth philtrum typical of a child with FAS. This ruler, developed by the University of Washington FAS Diagnostic and Prevention Network (FAS DPN), is intended for use by health professionals. Currently, there are two guides available for use: one validated for White individuals and another validated for Black or African American individuals. The guide has also been translated into Russian. It is important to note that these tools are typically used as part of the 4-Digit Diagnostic Code

system developed by the FAS Diagnostic and Prevention Network (DPN) and used by many diagnostic clinics across the country. This tool was adopted by the developers of the 2004 FAS Guidelines because it offers an accurate way for health care professionals to measure lip thinness and philtrum smoothness, and it can be used in a practice setting with relative ease. For more information on the lip-philtrum guide, go to http://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm.

Palpebral fissure length. Palpebral fissure length is the distance from the endocanthion (inner corner) to the exocanthion (outer corner) of the eye. In addition to having anomalies associated with the upper lip and the philtrum, individuals with FAS also present with small palpebral fissures (eye openings). Measuring palpebral fissure length can be quite challenging and research on standardizing these measures, particularly in newborns and children, is somewhat limited. Also, ethnic variation occurs in palpebral fissure length.

More information about how to measure these facial features is located in the Appendix of this Curriculum.

B. Growth Problems

While growth retardation has been documented consistently for children with FAS, it has not always been defined consistently. The recent guidelines (2004) propose the following growth retardation criteria:

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

It is important to keep in mind that growth problems occur for various reasons. Insufficient nutrition and environmental and genetic factors should be considered when assessing growth problems. The examiner should make sure that the single point in time when the growth deficit was present does not correlate with a point in time when the child was nutritionally deprived.

CDC's 2000 growth charts should be used to assess growth. Copies of these growth charts are available in the Appendix and are available online at www.cdc.gov/growthcharts.

C. Central Nervous System Abnormalities

More than 2,000 scientific papers have been published over the past 30 years on the teratogenic effects of alcohol exposure on the central nervous system. Even so, the scientific evidence and professional consensus on the CNS criteria for FAS are not yet at the level of specificity that is available for physical features of the condition. The 2004 FAS guidelines, however, do offer general recommendations to assist health care providers in identifying areas of abnormality most likely to be found in individuals with FAS, specifically as they relate to functional deficits.

CNS abnormalities can be structural, neurological, or functional. Documentation of problems in one or more of these areas is necessary for the FAS diagnosis. The criteria for CNS abnormalities are summarized below.

1. **Structural.** One way structural anomalies are assessed is by measuring the occipitofrontal circumference (OFC) or head circumference. OFC is typically measured at the place where the largest measurement can be obtained. The health care provider should refer to the appropriate head circumference chart to determine the percentile under which the patient falls. The criteria for FAS diagnosis is one or both of the following:

    - Head circumference (OFC) at or below the 10th percentile adjusted for age and sex
    - Clinically significant brain abnormalities observable through imaging

2. **Neurological.** Neurological problems not due to a postnatal insult or fever, or other soft neurological signs outside normal limits (e.g., poor coordination, visual motor difficulties, nystagmus, or difficulty with motor control).

3. **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:

    - Cognitive or developmental deficits or discrepancies
    - Executive functioning deficits
    - Motor functioning delays
    - Problems with attention or hyperactivity
    - Poor social skills
    - Other, such as sensory problems, pragmatic language problems, memory deficits, etc.

See Table 5.1 for examples of functional deficits in each of these domains.

Table 5.1. Identifying Functional CNS Deficits

(Deficits must be evident in three domains to confirm CNS abnormality for FAS diagnosis)

Functional Domain	Examples*
Cognitive or evelopmental deficits or discrepancies	Specific learning disabilities (especially math and/or visual-spatial deficits); uneven profile of cognitive skills; poor academic achievement; discrepancy between verbal and nonverbal skills; and slowed movements or reaction to people and stimuli (e.g., poor information processing).
Executive functioning deficits	Poor organization, planning, or strategy use; concrete thinking; lack of inhibition; difficulty grasping cause and effect; inability to delay gratification; difficulty following multi-step directions; difficulty changing strategies or thinking of things in a different ways (i.e., perseveration); poor judgment; and inability to apply knowledge to new situations.
Motor functioning delays	Delayed motor milestones; difficulty with writing or drawing; clumsiness; balance problems; tremors; and poor dexterity. For infants, a poor suck is often observed.
Attention deficit or hyperactivity	Described as "busy," inattentive; easily distracted; difficulty calming down; overly active; difficulty completing tasks; and/or trouble with transitions. Parents might report inconsistency in attention from day to day (e.g., "on" days and "off" days).
Poor social skills	Lack of stranger fear; often the scapegoat; naiveté and gullibility; easily taken advantage of; inappropriate choice of friends; preference for younger friends; immaturity; superficial interactions; adaptive skills significantly below cognitive potential; inappropriate sexual behaviors; difficulty understanding the perspective of others; poor social cognition; and clinically significant inappropriate initiations or interactions.
Other	Sensory problems (e.g., tactile defensiveness and oral sensitivity); pragmatic language problems (e.g., difficulty reading facial expressions; poor ability to understand the perspectives of others); memory deficits (e.g., forgetting well-learned material, needing many trials to remember); and difficulty responding appropriately to common parenting practices (e.g., not understanding cause-and-effect discipline).

*These examples are not exhaustive nor mutually exclusive. All domains should be assessed using norm-referenced standardized measures and by appropriate professionals using reliable and validated instruments.

Source: Adapted from Bertrand, J., Floyd, R. L., Weber, M. K., O'Connor, M., Riley, E. P., Johnson, K. A., Cohen, D. E., & National Task Force on FAS/FAE. Fetal alcohol syndrome: Guidelines for referral and diagnosis. Atlanta, GA: Centers for Disease Control and Prevention; 2004.

Considerations about CNS abnormalities. Differential diagnosis of CNS abnormalities involves not only ruling out other disorders but also specifying co-occurring disorders. The CNS deficits associated with FAS, in particular functional deficits, can be produced by many different factors in addition to prenatal alcohol exposure. It is important to determine that the observed functional deficits are not better explained by other causes. In addition to other organic syndromes that produce deficits in one or more of the previously cited domains (e.g., Williams syndrome and

Down syndrome), significantly disrupted home environments or other external factors can produce functional deficits in multiple domains that overlap with the domains affected by FAS.

In making the differential diagnosis of FAS by ruling out other syndromes, CNS abnormalities should be evaluated in conjunction with dysmorphia and laboratory findings. The more difficult differentiation is for CNS abnormalities resulting from environmental influences (e.g., abuse or neglect, disruptive homes, and lack of opportunities). Obtaining a complete and detailed history for the individual and his or her family can help health care providers make a differential diagnosis between FAS and environmental causes for CNS abnormalities.

In addition to ruling out other causes for CNS abnormalities, a complete diagnosis should identify and specify other disorders that can co-exist with FAS (e.g., autism, conduct disorder, and oppositional defiant disorder). It is very important to note that a particular individual might have a conduct disorder in addition to FAS, but that not all persons with a conduct disorder have FAS, and not all individuals with FAS have a conduct disorder. Thus, organic causes, environmental contributions, and comorbidity should all be considered for both inclusive and exclusive purposes when evaluating someone for the FAS diagnosis. Finally, differential diagnosis for the CNS abnormalities within the FAS diagnosis is extremely difficult and should be conducted by professionals trained not only in the features of FAS, but also in the features of a broad array of birth defects and developmental disabilities so as to understand the distinguishing characteristics. Table 5.2 summarizes the diagnostic criteria for FAS.

Table 5.2. Brief Outline of Diagnostic Criteria for Fetal Alcohol Syndrome

Criteria for FAS Diagnosis

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

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

C. 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).

D. Central nervous system abnormalities

Structural
- Head circumference (OFC) at or below the 10th percentile adjusted for age and sex.
- Clinically significant brain abnormalities observable through imaging.

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

Functional
Performance substantially below that expected for an individual's age, schooling, or circumstances, as evidenced by:

1. *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
2. *Functional deficits* below the 16th percentile (1 standard deviation below the mean for standardized testing) in at least three of the following domains:
   - Cognitive or developmental deficits or discrepancies
   - Executive functioning deficits
   - Motor functioning delays
   - Problems with attention or hyperactivity
   - Poor social skills
   - Other (e.g., sensory problems, pragmatic language problems, or memory deficits)

E. Maternal Alcohol Exposure
   1. Confirmed prenatal alcohol exposure
   2. Unknown prenatal alcohol exposure

Source: Adapted from Bertrand, J., Floyd, R. L., Weber, M. K., O'Connor, M., Riley, E. P., Johnson, K. A., Cohen, D. E., & National Task Force on FAS/FAE. Fetal alcohol syndrome: Guidelines for referral and diagnosis. Atlanta, GA: Centers for Disease Control and Prevention; 2004.

D. Maternal Alcohol Exposure

Documenting maternal alcohol exposure is important but it is often difficult to obtain. Birth mothers may feel stigmatized and are hesitant to admit to using alcohol during pregnancy; they also may still be drinking. For children in foster care or adoptive homes, it is especially difficult to get information on maternal alcohol use.

Although every effort should be made to obtain information on maternal alcohol use, it is not essential to making the FAS diagnosis. The presence of all diagnostic criteria (face, growth, CNS) alone is enough to diagnose FAS.

Given the imprecise nature of gathering exposure information, definitions of confirmed and unknown prenatal alcohol exposure are provided in the new FAS guidelines:

- **Confirmed prenatal alcohol exposure.** Documentation of the alcohol use patterns of the birth mother during the index pregnancy based on clinical observation; self-report; reports of heavy alcohol use during pregnancy by a reliable informant; medical records documenting positive blood alcohol levels or alcohol treatment; or other social, legal, or medical problems related to drinking during the index pregnancy.
- **Unknown maternal alcohol exposure.** Neither the presence nor absence of exposure can be confirmed. Examples include instances in which the child is adopted and prenatal exposure(s) is unknown; the birth mother is an alcoholic, but confirmed evidence of exposure during pregnancy does not exist; and conflicting reports about exposure cannot be reliably resolved.

E. Need for criteria for other alcohol-related disorders

It is important to note that the CDC FAS guidelines are not intended to be an endpoint in the discussion of diagnosing FAS. There is a great need to acquire science-based information that will facilitate diagnostic criteria for additional related disorders, such as alcohol-related neurodevelopmental disorder (ARND). The guidelines conclude with a call for further research and continuous refinement of the diagnostic criteria for FAS and related conditions so that affected individuals and their families can receive important services that enable them to achieve healthy lives and reach their full potential.

III. Considerations for a Referral for an FAS Diagnostic Evaluation

This section is adapted from Bertrand, J., Floyd, R. L., Weber, M. K., O'Connor, M., Riley, E. P., Johnson, K. A., Cohen, D. E., & National Task Force on FAS/FAE. Fetal alcohol syndrome: Guidelines for referral and diagnosis. Atlanta, GA: Centers for Disease Control and Prevention; 2004.

Very often, front-line providers of services (medical, educational, or social) are faced with deciding whether or not to refer a child, individual, or family for a full FAS diagnostic evaluation. For biological families, there might be social stigma associated with any evaluation concerning prenatal alcohol exposure. In other families, direct information about alcohol use during pregnancy might be unavailable or only suspected. Thus, the following guidelines were developed to provide assistance in making the referral decision, although it is recognized that each case must be evaluated individually. Further, these guidelines were developed with the idea that when in doubt, it is preferable to refer for full evaluation by a multidisciplinary team with experience in evaluating prenatal alcohol exposure.

For situations with known prenatal alcohol exposure. A child or individual should be referred for full FAS evaluation when there is confirmed significant prenatal alcohol use (i.e., seven or more drinks per week or three or more drinks on multiple occasions, or both). If prenatal alcohol exposure in the high-risk range is known, the primary health care provider should document this exposure and closely monitor the child's ongoing growth and development, even in the absence of any other positive screening criteria.

For situations with unknown prenatal alcohol exposure. A child or individual should be referred for full FAS evaluation when:

- There is any report of concern by a parent or caregiver (foster or adoptive parent) that his or her child has or might have FAS.
- All three facial features are present (smooth philtrum, thin vermillion, and small palpebral fissures).
- One or more facial features are present in addition to growth deficits in height, weight, or both.
- One or more facial features are present, along with one or more CNS abnormalities.
- One or more facial features are present, along with growth deficits and one or more CNS abnormalities.

IV. Evaluation of Fetal Alcohol Spectrum Disorders

Blair Paley, PhD, Amy Schonfeld, PhD, Mary J. O'Connor, PhD

A. Characteristics of Fetal Alcohol Spectrum Disorders

Fetal alcohol syndrome (FAS) is caused by maternal consumption of alcohol during pregnancy and characterized by a distinct cluster of characteristic facial features, growth retardation, and central nervous system dysfunction. It is arguably the most significant cause of developmental disabilities of known etiology (Jones & Smith, 1973). An extensive body of literature has documented significant cognitive, behavioral, and emotional difficulties among individuals with FAS (Burd, Klug, Martsolf, & Kerbeshian, 2003; Kodituwakku, 2007; Mattson & Riley, 1998; O'Connor, 2001; Olson, Morse, & Huffine, 1998; Rasmussen, 2005; Streissguth et al., 2004), as well as among children who have been prenatally exposed to alcohol but do not meet the full criteria for FAS (Kvigne et al., 2004; Mattson & Riley, 1998; Schonfeld, Mattson, & Riley, 2005). This latter group of individuals might be diagnosed with partial FAS, alcohol-related neurodevelopmental disorder (ARND), or alcohol-related birth defects (ARBD), and together with those diagnosed as having FAS, are increasingly being referred to under the larger rubric of fetal alcohol spectrum disorders (FASDs) (Warren et al., 2004). Estimates of the number of live births in the United States meeting criteria for a diagnosis of FAS range from 0.5 to 2 infants per 1,000, with the prevalence of the entire continuum of FASDs estimated to be 1 in 100 (May & Gossage, 2001). The cost of FAS alone for the United States has been estimated to be more than $2 billion per year (Harwood, Fountain, & Livermore, 1998).

A number of facial characteristics are frequently described in individuals with FAS, but three are considered to be central to this diagnosis: short palpebral fissures, a thin vermillion border or upper lip, and a smooth or flattened philtrum (Astley, 2004; Astley & Clarren, 2000; 2001). These facial anomalies associated with FAS are thought to be secondary to the impact of alcohol on early brain development (Jones, 2003). Although not considered central to the diagnosis of FAS, a number of other physical anomalies are associated with (but not necessarily unique to) prenatal alcohol exposure, including epicanthal folds, ptosis, strabismus, "railroad track" ears, small upturned nose, flattened nasal bridge, maxillary hypoplasia, dental malocclusions, cleft palate, narrow- or high-arched palates, "hockey stick" or other abnormal palmar creases, camptodactyly and clinodactyly, nail hypoplasia, joint contractures, and cardiac defects (Autti-Rämö et al., 2006; Church, Eldis, Blakley, & Bawle 1997; Jones, 2003; Jones, Smith, Ulleland, & Streissguth, 1973; May et al., 2006).

There is evidence from both animal and human studies that prenatal exposure to alcohol is associated with growth deficits, and these deficits are apparent at birth and in early infancy (Day & Richardson, 2004) and into childhood (Klug, Burd, Martsolf, & Ebertowski, 2003) and adolescence (Day et al., 2002). The relationship between prenatal alcohol exposure and growth deficiency appears to be linear, with effects documented even at relatively low levels of exposure (Day & Richardson, 2004). Additionally, the time of exposure might also determine the level of growth effects (Day et al., 1989; Streissguth, Martin, Martin, & Barr, 1981). Not surprisingly, however, the most significant growth deficits appear to be associated with continuous and heavy drinking throughout the pregnancy (Smith, Coles, Lancaster, Fernhoof, & Falek, 1986). These growth effects might persist in many, but not all, individuals exposed to alcohol prenatally. Such

variations might be a function of interactions between the individual's prenatal exposure and postnatal environment, with growth effects more likely to persist among individuals from less advantaged backgrounds (Day & Richardson, 2004).

Although the facial dysmorphology and growth retardation associated with prenatal alcohol exposure are perhaps more easily identified, the most damaging effects are abnormalities of the central nervous system (CNS), which affect neurocognitive functioning. A growing body of research has shown that individuals exposed to alcohol prenatally exhibit "structural alterations… in brain size, shape, and symmetry" (McGee & Riley, 2006, p. 46). Additionally, abnormalities in specific brain structures are well-documented, including the corpus callosum, cerebellum, and basal ganglia (McGee & Riley, 2006; Riley & McGee, 2005; Riley, McGee, & Sowell, 2004; Spadoni, McGee, Fryer, & Riley, 2007).

In general, the majority of alcohol-exposed individuals do not have significant intellectual disability or mental retardation, but individuals with FASDs exhibit lower overall intellectual functioning compared with the general population (Mattson, Riley, Gramling, Delis, & Jones, 1997; May et al., 2006; Streissguth & O'Malley, 2000). For example, in a sample of 415 adolescents and adults, patients diagnosed with FAS had a mean IQ of 80, and those diagnosed with fetal alcohol effects (FAE) had a mean IQ of 88 (Streissguth et al., 2004). In a sample of children with prenatal alcohol exposure, Mattson et al. (1997) found a mean IQ of 74 among those who met full criteria for FAS, and a mean IQ of 83 for those who did not exhibit the physical features of FAS.

Additionally, evidence for some consistent neurocognitive deficits has emerged. Verbal learning and memory problems; attention deficits; problems in abstract and practical reasoning; and problems in executive functioning characterized by difficulties in planning, organizing, and sequencing behavior appear to be prominent in individuals with prenatal alcohol exposure (Adnams et al., 2001; Coles et al., 1997; Connor, Sampson, Bookstein, Carr, & Streissguth, 2000; Kodituwakku, 2007; Kodituwakku, Kalberg, & May, 2001; Mattson, Goodman, Caine, Delis, & Riley, 1999; Mattson & Riley, 1998; Rasmussen, 2005). Executive functioning deficits in the areas of complex nonverbal problem solving (Mattson et al., 1999), flexible thinking (Kodituwakku et al., 1995; Mattson et al., 1999; Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998; Schonfeld, Mattson, Lang, Delis, & Riley, 2001), and behavioral inhibition (Kodituwakku et al., 1995; Mattson et al., 1999) have also been reported. Importantly, these deficits are found both in exposed individuals who meet the full criteria for FAS and in those who do not (Connor et al., 2000; Kodituwakku et al., 2001; Mattson et al., 1998; Mattson et al., 1999), and they persist into adulthood (Connor et al., 2000; Olson, Morse et al., 1998; Streissguth & O'Malley, 2000; Streissguth et al., 1991). Moreover, executive functioning problems do not appear to be merely a reflection of lower cognitive abilities among individuals with prenatal alcohol exposure. That is, deficits in executive functioning have been found to be greater in exposed individuals than what would be expected based on IQ scores (Connor et al., 2000); other studies have demonstrated that problems with executive functioning are still apparent when controlling for IQ (Kodituwakku et al., 2001; Schonfeld et al., 2001).

A number of researchers have also examined the association between prenatal alcohol exposure and adaptive functioning, or the ability to independently perform developmentally expected tasks associated with daily living, such as self-care, communication, and social skills.

In a sample of clinic-referred alcohol-exposed children, Whaley, O'Connor, and Gunderson (2001) found deficits across the communication, daily living, and socialization domains of the Vineland Adaptive Behavior Scales. Similarly, Streissguth and colleagues (2004) found children, adolescents, and adults with FAS or FAE to exhibit significant impairments across all three domains of the Vineland Adaptive Behavior Scales.

Several studies have focused on deficits in the social domain in particular. Prenatally exposed children have shown 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 (Coggins, Friet, & Morgan, 1997; Olson, 1994; Streissguth, 1997; Streissguth et al., 1991). Children with prenatal alcohol exposure have been rated by both their caregivers (Roebuck, Mattson, & Riley, 1999) and teachers (Brown et al., 1991) as having poorer social skills than unexposed children. Thomas, Kelly, Mattson, and Riley (1998) conducted a study to compare children with prenatal alcohol exposure and unexposed children with similar deficits in verbal IQ. Results revealed that children with prenatal exposure were more impaired interpersonally than developmentally delayed children, suggesting that social deficits in these children cannot be explained by low IQ scores alone. These findings of social deficits as a function of prenatal alcohol exposure are fairly robust and have been replicated in cross-cultural studies and using multiple methods (Adnams et al., 2001; Kelly, Day, & Streissguth , 2000). Moreover, studies of adolescents and adults with FASDs indicate that social skills deficits are maintained well past childhood (LaDue, Streissguth, & Randels,1992; Streissguth et al., 1991) and thus represent a particularly important focus of assessment and intervention.

Finally, numerous studies have identified high rates of secondary disabilities among individuals with fetal alcohol syndrome or other alcohol-related conditions. For example, children and adults with FASDs present with high rates of psychiatric co-morbidity (Bhatara, Loudenberg, & Ellis, 2006; Burd, et al., 2003; Famy, Streissguth, & Unis, 1998; O'Connor, Shah, et al., 2002; Steinhausen & Spohr, 1998; Streissugth & O'Malley, 2000) and are overrepresented in psychiatric samples (O'Connor, McCracken & Best, 2006). Individuals with FASDs also experience significant school and work problems and are much less likely to be able to live independently (Aronson & Hagberg, 1998; Streissguth & O'Malley, 2000). Of particular concern is an increased risk for delinquency (Schonfeld et al., 2005) and trouble with the law, including committing criminal acts against others and being charged, arrested, and/or convicted of a criminal offense (Streissguth et al., 2004). FASDs appear to be overrepresented (Fast, Conry, & Loock, 1999), yet often underidentified (Burd, Selfridge, Klug, & Bakko, 2004), in juvenile detention and correctional settings.

B. Overview of the Assessment Process

1. **Multidisciplinary collaborative approach.** Professionals working with individuals with FASDs and their families have recognized that a multidisciplinary collaborative approach is optimal when conducting an assessment of an individual with prenatal alcohol exposure (Centers for Disease Control and Prevention, 2005; Chudley et al., 2005; Olson & Clarren, 1996). Individuals affected by prenatal alcohol exposure often present with challenges in multiple domains of functioning, and thus can benefit from working with a team of professionals who possess expertise across those various domains. Such an approach is likely to lead to more accurate diagnostic decisions and to more comprehensive treatment plans.

An integrated approach is particularly important because impairments in one domain of functioning (e.g., behavior, language) might often interfere with functioning in another domain (e.g., social, academic), and affected individuals are done a disservice when care is not coordinated across different specialists. By capitalizing on the expertise and skills of each of its members, a multidisciplinary team can provide an integrative, detailed assessment of an alcohol-affected individual's primary areas of difficulty, as well as his or her strengths and resources, and recommend interventions that target the individual's and his or her family's specific areas of need. Such a team might include physicians, psychologists, social workers, speech-language pathologists, educational therapists, occupational therapists, physical therapists, public health nurses, advocates, and others.

2. **Contextual approach.** When assessing an individual with prenatal alcohol exposure, it is important to consider the context in which the individual lives or is being raised. First, family compositions vary considerably, and many individuals do not grow up in traditional two-parent households. There are single-parent households, reconstituted households, multigenerational households, multiethnic households, and households headed by two same-sex parents, to name just a few. Moreover, family members or other important caregivers (e.g., grandparents, family friends) who do not reside in the same household might play an important role in the affected individual's life. The assumption should not be made that important care giving figures must either be biologically related to the individual or reside in the same home as the individual in order to play an important role in their life. Indeed, it might be extremely beneficial to include such individuals in the evaluation and/or treatment planning process.

   Clearly the current environment in which an individual with prenatal alcohol exposure lives, and the care and support provided to him/her by others, can play a profoundly important role in ameliorating the risks conferred by his or her prenatal history. In their longitudinal study of adolescents and adults with FASDs, Streissguth and colleagues (2004) found that being raised in a stable, nurturing home is one of the strongest protective factors against secondary disabilities, including disrupted school experiences, problems with the law, confinement in a legal or psychiatric facility, and substance abuse problems. In addition to assessing factors in the current environment, a comprehensive evaluation should also focus on aspects of the alcohol-affected individual's past environment that might continue to exert an influence on his or her current functioning. Histories of past abuse, neglect, or deprivation, exposure to trauma, and disrupted attachment experiences, for example, can all have significant and long-lasting effects on an individual's development even if the individual has since been placed in a more supportive and stable environment. This is an especially important consideration when working with individuals affected by prenatal alcohol exposure, as many of these individuals are in foster care or have been adopted. The prevalence of FAS in the foster care population has been estimate to be 10–15 times higher than in the general population (Astley, Stachowiak, Clarren, & Clauseen, 2002). Several studies have shown that many alcohol-affected children experience one or more changes in custody during their lives, either being placed in foster care or up for adoption, or being institutionalized (Stratton, Howe, & Battaglia, 1996). It has been estimated that two thirds of affected children are not raised in their biological homes (National Organization on Fetal Alcohol Syndrome, 2002), and many experience multiple placements in their lifetime,

often of varying quality. Thus it is critical in any evaluation of an alcohol-affected individual to examine factors in their current or past environment that might serve to enhance, or alternatively, to impede their development and functioning.

It is also important to assess current caregivers' sensitivity to and understanding of the potential impact of the past environment on the individual's development. Many adoptive/foster parents of individuals affected by prenatal alcohol exposure might believe that providing a nurturing, stimulating environment should ameliorate many, if not all, of the individual's difficulties. Parents and caregivers have sometimes been given such assurances by professionals. Indeed, anecdotal accounts by parents indicate that they believed (or were told) that their foster or adopted child would be "okay," since he or she was exposed "only" to alcohol, and not other substances, such as cocaine or heroin. Other parents have been offered reassurances by well-meaning medical or mental health professionals that providing a nurturing, loving environment would be sufficient in resolving many, if not all, of the risks incurred by the child as a function of either their prenatal or early postnatal environment. Not surprisingly, caregivers can become frustrated, disappointed, and even demoralized if the affected child continues to experience significant difficulties despite their best efforts to provide support and resources for their child. Thus, it is important to assess families' understanding of how the individual's previous environment (both prenatal and postnatal) might continue to affect him or her, and what their expectations were for the affected individual's prognosis, in order to determine what kind of education, support, and resources might be most helpful.

Contextual considerations also should include examining how the individual interacts within his or her family, community, and culture. It is important to consider the individual's transactions with other individuals such as parents, spouses/partners, children, teachers, friends, co-workers, and even other medical or mental health professionals, etc. Transactions between the individual and his or her family and other important figures in his or her life should be viewed as reciprocal and mutually influential—that is, individuals both impact and are impacted by their environment (Cox & Paley, 1997; Minuchin, 1985). For example, parents of children affected by prenatal alcohol exposure report high levels of stress (Paley, O'Connor, Frankel, & Marquardt, 2006; Paley, O'Connor, Kogan, & Findlay, 2005); this stress is believed to be caused in part by impairments in the child's adaptive, behavioral, and executive functioning (Paley et al., 2006). However, it is also equally plausible that highly stressed parents or other family members might act in ways that further exacerbate an individual's existing difficulties (Östberg & Hagekull, 2000). The perspective that individuals both influence and are influenced by their environment is important not only when gathering information about the individual and his or her environment, but also when devising a treatment plan. That is, interventions that are aimed at an individual with prenatal alcohol exposure are also likely to impact his or her environment (e.g., improvements in an individual's behavioral problems will likely lead to decreases in his or her parents' stress), and interventions aimed at the environment will likely affect the individual (e.g., parents who are provided with better support and directed to helpful resources might have more energy and confidence in effectively managing their child's behavioral problems).

In addition to considering family factors, assessment of an individual with prenatal alcohol exposure should take into account the individual's community and his or her sociocultural

background. Such factors might affect how the individual and his or her family view disabilities in general and FASDs in particular, as well as how they interact with medical and mental health professionals and how such professionals interact with them. Sociocultural factors should certainly be considered when selecting an assessment battery, and when interpreting the results of the assessment. Sociocultural factors might impact the interview process, in terms of how the team members and the affected individual and his or her family members interact, even with respect to the very questions that are asked, and how such questions are interpreted and answered. Regarding treatment planning, there might be important resources in the individual's community or culture (e.g., parent/caregiver support groups, religious or spiritual institutions) that can be mobilized to assist the individual and his or her family.

3. **Developmentally sensitive approach.** The age and developmental level of the affected individual also have relevance for the assessment process. Developmental issues should be considered (a) when assessing why the individual has come or been brought in for an assessment; (b) when assessing the family's understanding of and expectations about the individual's abilities and functioning, as well as the expectations of those who work with the child, such as teachers or therapists; and (c) when devising a treatment plan and providing feedback and recommendations to the family.

   It is important to recognize that FASDs are associated with lifelong impairments, and are not disorders that are "outgrown" (Streissguth, 1997). However, because the sequelae of FASDs might manifest differently at various developmental stages, parents and families are likely to have different concerns depending on the child's chronological and developmental age (Olson & Clarren, 1996). The effects of prenatal alcohol exposure are evident from infancy in both animals (Schneider, Roughton, & Lubach, 1997) and humans (e.g., Smith et al., 1986; Streissguth, Barr, & Martin, 1983). Researchers have demonstrated that in infancy, prenatal alcohol exposure is associated with increased negative affect and higher rates of insecure attachment behavior (O'Connor, 2001; O'Connor, Sigman, & Kasari, 1992), poorer habituation (Streissguth et al., 1983) and orientation (Smith et al., 1986), problems with state (Streissguth et al., 1983) and autonomic (Smith et al., 1986) regulation, increased post-stress cortisol levels (Jacobson, Bihun, & Chiodo, 1999), and less mature motor behavior and increased level of activity (Coles, Smith, Fernhoff, & Falek, 1985). Feeding difficulties are not uncommon, and infants with prenatal alcohol exposure might present in medical settings with failure to thrive (Streissguth, 1997). During this early developmental period, parents might not see any association between the child's difficulties and prenatal alcohol exposure. They might instead assume that the child simply has a difficult or irritable temperament and, thus might not be inclined to seek any help at this point.

   As children enter preschool or kindergarten, behavioral problems might emerge or become more salient, and parents and caregivers might be increasingly motivated to seek professional help. For many parents, this might be their first time seeking an evaluation for their child. Some parents might identify prenatal alcohol exposure as a possible contributing factor to their child's difficulties; others might see no connection or be unaware of their child's prenatal history. Some parents of preschoolers might be surprised and confused by their child's problems, and feel overwhelmed at the prospect of having to seek intervention for their child. On the other hand, Olson and Clarren (1996) have noted that "parents of

preschool aged alcohol-affected children typically have more energy and hope" (p. 3) since more serious developmental and behavioral problems develop later.

During early and middle childhood, parents of children with FASDs might be most focused on learning and academic problems. Increased rates of learning disorders have been reported among children with FAS (Burd et al., 2003), and many end up in special education (Aronson & Hagberg, 1998). Children with prenatal alcohol exposure also exhibit high rates of externalizing behavior and attention problems (Bhatara et al., 2006; Sood et al., 2001), and such problems are likely to interfere significantly with school performance. A child might be bringing home poor grades, having difficulty completing his or her homework, and getting into trouble for his or her impulsive or disruptive behavior in class. Parents might hear complaints from frustrated teachers regarding the child's apparent mastery of a skill one day and complete inability to perform that same skill the following day. Some teachers might view the child's difficulty following directions as willful noncompliance rather than as a reflection of cognitive or executive functioning problems. Although perhaps less likely to attract the notice of parents and teachers, the emergence of internalizing problems and mood disorders has also been observed in children with prenatal alcohol exposure during this period (O'Connor & Paley, 2006; O'Connor, Shah, et al., 2002). Parents might also begin to notice that their child is not faring well socially, although these concerns are often secondary to those regarding the child's academic functioning. Parents often comment that their children are rarely invited to birthday parties, are not invited over to other children's homes more than once, and despite being quite friendly, do not seem to have any real friends. By this point, some children with FASDs might have received numerous evaluations, none of which have recognized prenatal alcohol exposure as a factor contributing to the child's difficulties, and parents might feel quite frustrated that not only are their child's problems not getting better, but they appear to be getting worse.

Parents of adolescents with FASDs might begin to worry about victimization, high-risk behavior, and delinquency (Olson & Clarren, 1996), and seemingly with good reason. Schonfeld and collaborators (2005) reported increased rates of delinquency among adolescents with prenatal alcohol exposure and found that deficits on a measure of sociomoral values were predictive of these higher rates of delinquent behavior. Difficulties with maintaining appropriate physical boundaries and navigating peer and romantic relationships might become particularly salient among adolescents with FASDs. Streissguth and colleagues (2004) found that 58% of adolescents with FAS or FAE had trouble getting along with peers, and 48% had engaged in inappropriate sexual behavior, most commonly promiscuity and inappropriate sexual advances. School problems are also likely to continue to be a major concern. Streissguth and colleagues (2004) found that approximately 53% of adolescents with FAS or FAE had been suspended, 29% had been expelled, and 25% had dropped out of school. During this period, parents might be especially concerned about their adolescent's prospects for leading a productive and independent life, and many might see their adolescent perched on the precipice of a downward spiral. If the adolescent has never received a diagnosis of FAS (or related condition), such a diagnosis might not only help redirect intervention in a more productive manner, but might also play an important role in educational planning meetings and even legal proceedings. For example, a diagnosis of FAS might lead school personnel to view an adolescent who is on the verge of being expelled for behavioral problems in a different manner.

For many affected adults, basic tasks of daily living, such as maintaining steady employment, managing money, and obtaining medical care present major challenges (Streissguth, 1997). Furthermore, Olson and Clarren (1996) have noted that parents of alcohol-exposed adults "are dealing with their own mortality and the accumulation of secondary disabilities in their adult child" (p. 3) such as trouble with the law and long-term psychiatric disabilities. Such concerns do not appear to be unfounded given the poor long-term outcomes documented among adults with FAS or FAE. Using structured diagnostic interviews, Famy and colleagues (1998) found high rates of psychiatric disorders among adults diagnosed with FAS or FAE, including alcohol or drug dependence, depression, psychotic disorders, and various personality disorders. Streissguth and colleagues (2004) reported that 60% of adults with FAS or FAE had problems with the law, and 50% had either been incarcerated or hospitalized in a psychiatric facility. Unfortunately, evaluations for alcohol-affected adults are sometimes sought in the context of serious legal proceedings, including death penalty cases, further highlighting the critical importance of early diagnosis and intervention.

arents or caregivers might have inappropriate expectations for the alcohol-affected individual if they don't understand that he or she might be functioning at a developmental level that is discrepant with his or her chronological age. Consequently, it is important to assess parents' or caregivers' expectations for the individual and their understanding of the individual's abilities in light of his or her developmental level. Notably, individuals with FASDs often exhibit adaptive skills (Streissguth & O'Malley, 2000) and executive functioning (Connor et al., 2000) that are considerably lower than their cognitive functioning, which might lead parents to be frustrated when their child is unable to negotiate tasks of everyday living that would be seemingly commensurate with his or her general cognitive abilities. Similarly, teachers might view alcohol-affected students with normal IQs as noncompliant rather than as impaired when these students forget to complete their homework, fail to adhere to well-established classroom routines, or fail to follow seemingly simple instructions. Thus, a thorough evaluation must assess not only the individual's actual developmental level, but others' perceptions about the individual's developmental level as well.

The feedback that is provided to the family, including the diagnosis and the treatment plan, must also take into account the individual's age and developmental level. Families of young children might have greater difficulty accepting the diagnosis, particularly if the child is not yet exhibiting significant behavioral or academic problems. Such families might also press clinicians for a clear picture of the child's prognosis (e.g., "Will my child go to college?"), which might be difficult for the team to provide at that point. Families of older children or adults might feel relief at finally having some explanation for the individual's difficulties, but they might still have strong feelings of loss, anger, and guilt about the diagnosis. Regarding the treatment plan, it is imperative that the child's age and developmental level be taken into account when outlining potential interventions for the family. Such interventions should be aimed at achieving developmentally appropriate goals—that is, such goals should be set high enough so that both the individual and the family have something to strive for, but not so high that they are set up for failure. If referrals are made to specific clinicians or treatment programs, the team should ensure that these clinicians or programs have experience working with individuals in the same age range and developmental level (i.e., if a 6-year-old patient requires a medication evaluation, the family should be referred to a board-certified or board-

eligible child psychiatrist with expertise in FASDs, rather than a psychiatrist who works primarily with adults).

4. **Goals of the assessment.** The goals of a multidisciplinary, culturally sensitive, comprehensive assessment of individuals with prenatal alcohol exposure are as follows:

   - Determine what the family (and possibly the individual) would like to learn from the assessment and learn about the family's perspective on disabilities in general and understanding of FASDs in particular.
   - Assess the individual's current level of functioning—both his or her areas of difficulty and his or her strengths and resources.
   - Assess the interactions and relationships between the individual and his or her family and other important figures in the individual's life.
   - Develop an understanding of how sociocultural factors might be influencing the individual's development and his or her family's functioning.
   - Determine what services and resources have already been accessed on behalf of the individual and the family.
   - Provide specific, concrete, and viable recommendations for treatment and intervention that will optimize the functioning of both the individual and the important figures in his or her environment.

   In pursuing these goals, the assessment team should aim to develop a collaborative and mutually respectful alliance with the family and the affected individual. To develop a deep understanding of the individual and his or her environment, the team must seek to form a relationship with the family so that a plan can be made to provide the support that is needed. In order for a family to benefit from clinical service, an atmosphere of cooperation and trust must be developed. The team must show empathic concern and respect for the family's wishes and needs. The team needs to be careful not to be judgmental but rather to serve as a partner to help the family.

   Developing a collaborative relationship with families of individuals affected by prenatal alcohol exposure can present unique challenges. Biological parents (especially mothers) of children affected by prenatal alcohol exposure might feel judged or blamed by the evaluation team, and team members must monitor if there is some basis for these feelings. Foster or adoptive parents might carry frustrations from working with other professionals who did not accurately diagnose the child or failed to recognize prenatal alcohol exposure as a major factor contributing to the child's difficulties, but rather attributed the child's problems to "bad parenting" or to the child being "bad" (Olson & Clarren, 1996). The evaluation team should anticipate the possibilities of these issues when working with families of individuals with prenatal alcohol exposure.

C. Components of the Evaluation*

1. **Comprehensive history.** Obtaining a comprehensive history for an alcohol-affected individual typically entails (a) a thorough review of birth and medical records and any records documenting previous evaluations or interventions (if available); (b) a clinical interview with parents, caregivers, and other important figures in the individual's life; and (c) a clinical interview with the individual if developmentally appropriate.

   a. *Record review.* A thorough review should be made of available birth records, medical records, reports concerning previous evaluations or interventions, and academic records (e.g., individual education programs, report cards). Ideally, such documentation should be obtained and reviewed before the family comes in for the evaluation. The team should attempt to obtain records of previous evaluations and treatment, rather than relying solely on parents' and caregivers' verbal reports of this information. Parents and caregivers might not be able to accurately recount prior testing or diagnoses, or they might not understand what diagnoses the individual has been given, what type of testing the individual has received (and the results of those tests), and what types of services the individual has received. Such information will guide the evaluation team in developing an assessment plan. For instance, it will help the team in determining whether previous tests can or should be re-administered and in comparing new testing results with previous testing results. Additionally, knowing what interventions have been implemented previously and whether or not they were successful, knowing what specific recommendations have been provided to the family and whether they were pursued by the family, determining whether the individual has been receiving an adequate level of services will also guide treatment planning.

      In the case of international adoptions, any records in the original language should be translated if possible. Sometimes, the English translations initially provided to the adoptive family by the adoption agency are missing important but "sensitive" information (i.e., whether the child's mother consumed alcohol during pregnancy). It should be noted, however, that many birth or medical records simply do not contain any information relevant to a possible history of prenatal alcohol exposure. For example, Burd and colleagues (2006) noted that in their review of several thousand charts of women who were either seeking prenatal care or were having their children evaluated for FASDs, the majority of those charts had little or no useful information about attempts to assess for maternal alcohol consumption during pregnancy. Thus, the lack of documentation of prenatal alcohol exposure in an individual's birth or medical record should not be taken as a reliable indicator that the individual does not have such a history.

   b. *Clinical interview with parents/caregivers or other professionals*

      i.) **Source of information.** One important issue to consider when conducting a clinical interview with parents, caregivers, or other professionals (e.g., the individual's social worker) is the extent to which such individuals might be able to provide reliable,

* Examples provided in this section are from a large, university-based clinic.

accurate information about the affected individual. Often the team might have little choice in who they can interview, but the quality of the information being provided should always be assessed. A number of issues bear mentioning with respect to quality of such information.

First, it is important to assess the extent to which parents and caregivers or other professionals are providing information of which they have personal knowledge, or whether they are reporting information they have acquired from some source of unknown reliability. It is not uncommon in the clinical process for information to become accepted as true by virtue of simply being repeated enough times without anyone checking the accuracy of the original information. For example, inaccurate information is sometimes communicated to parents and caregivers or written down in an individual's record (i.e., medical chart, psychological assessment report), but it becomes "fact" because it is repeated in successive documents and is never subsequently questioned. For example, in one case, several previous reports mentioned that there was no record or documentation of maternal use of alcohol during pregnancy, and thus the adoptive parents believed that the child had no history of prenatal alcohol exposure. However, rather than relying on these reports, the evaluation team went back to the original birth records (which were rather voluminous), and in reviewing chart notes, they discovered that both a nurse and a social worker had documented the mother's acknowledgment of consuming alcohol during the pregnancy.

Moreover, it is not unusual for alcohol-affected individuals to be brought in for evaluation by someone who might have had only recent or limited contact or experience with the individual (i.e., a social worker, a new foster parent). Although such individuals might be able to relate information about the individual's current functioning, it might be difficult for them to provide important historical information about the individual's pre- and postnatal development, previous evaluations and intervention, and family history. Consequently, information from multiple sources should be obtained if possible. For example, when assessing a foster child, the team might attempt to contact (if clinically appropriate and with the necessary releases) the biological parents or other biological relatives (e.g., grandparents, aunts or uncles, older siblings) either directly or through an intermediary, such as a social worker, for additional historical information.

Finally, when the alcohol-affected individual is brought in by biological family members, it is important to consider the potentially multigenerational nature of FAS. Thus, when interviewing family members, the team should assess not only whether the biological mother (and father) used alcohol pre- and postnatally, but also whether they themselves (as well as other extended family members) might have been affected by prenatal alcohol exposure. Such information has immediate implications for the evaluation process (i.e., their capacity to understand questions and provide accurate information), and long-term implications for both the intervention process (i.e., the family's capacity to access services and implement treatment recommendations) and the prevention of prenatal alcohol exposure among subsequent children in the family.

ii.) **Presenting concerns and reason for assessment.** Although initial information about presenting concerns and the family's reason is seeking an assessment has likely already been obtained through a screening process, it is important to elicit detailed information during the clinical interview regarding these issues. Eliciting such information during the interview will not only provide a comprehensive picture of the difficulties and challenges the individual and family have been facing, but also provide the family with an opportunity to "tell their story." Parents and caregivers are often exhausted from the stress of caring for an individual with FAS or a related condition, they might feel that the individual's difficulties are all their fault (and might have been overtly blamed by others for the individual's problems), and they might feel extremely isolated, particularly if they are not yet connected with any support services. Providing the family with a chance to air their concerns sets the stage for the team to form an empathic alliance with the family. It is also important to determine what the family is hoping will come about as a result of the evaluation. Some families might be fairly new to the evaluation process and not have a clear understanding of even why they are having an evaluation (i.e., "Our pediatrician told us to come").Other families might have very specific concerns and needs, and it's important to make sure that those concerns are addressed, if possible.

Information to be elicited during this part of the assessment includes the following:

- What the family hopes to learn or have happen as a result of the evaluation.
- A detailed description of the presenting concerns or problems, including specific examples—For instance, if the parents are concerned about "aggression," they should be asked to give a recent example of the individual's aggressive behavior.
- Course of the problems—When did they first start, when were they first noticed, have the problems waxed or waned, or did problems gradually or suddenly worsen?
- Context of the problems—Do the parents perceive there to be any identifiable precipitants, do the problems occur only or primarily in specific settings or across multiple settings, do the problems occur only or primarily with specific individuals or with a number of different people?
- Parents' and caregivers' response to these concerns or problems—Is there a greater focus on punishing negative behavior than on reinforcing positive behavior; is there a consistent response to the individual's behavior both across time and across caregivers?

As individuals with prenatal alcohol exposure might be relatively unaffected in one area, but quite affected in another, it is important to inquire about concerns across multiple domains of functioning, including cognitive, academic, adaptive, behavioral, social, emotional, and physical. As noted earlier, for example, an individual with FAS might have a normal IQ, but exhibit significant deficits in executive or adaptive functioning (Kodituwakku et al., 2001; Schonfeld et al., 2001; Streissguth & O'Malley, 2000).

It is also important to consider how parents present their concerns. For example, are they seeking an evaluation because they perceive the individual to be experiencing difficulties, or are they there at someone else's urging or insistence (i.e., child is about to be expelled from school)? What do they view as the cause of the individual's difficulties? Do they see some connection between the individual's difficulties and his or her prenatal exposure to alcohol, or do they attribute intentional "badness" to the individual, or do they blame themselves or one another? Such information can help the team anticipate how to present the diagnosis (if one is to be given) and treatment recommendations in a way that will enhance the family's receptivity to the team's feedback.

iii.) **Past evaluations and interventions.** The clinical interview should also include a review of what evaluations and interventions the alcohol-affected individual has previously received, including those in the academic setting such as those for individualized education programs. Information should be obtained regarding the type or nature of the evaluation or intervention, when it occurred, with whom (including contact information if appropriate), results or outcomes (including whether the parents and caregivers found it to be helpful), and whether any report or written documentation is available (if such documentation has not already been obtained). Such information will also provide some indication of whether the family is able to make use of treatment recommendations and to access services and support in the community.

It is especially important to find out whether interventions were informed by knowledge of the individual's prenatal alcohol exposure and attendant deficits. Researchers have recognized the importance of modifying extant interventions to accommodate the particular behavioral and cognitive impairments frequently seen in individuals with prenatal alcohol exposure in order to enhance the efficacy of those interventions (Laugeson et al., 2007; O'Connor et al., 2006). Clinically, it has been observed that interventions sometimes fail because they were provided without knowledge of the individual's prenatal exposure to alcohol or recognition that the individual would qualify for a diagnosis of FAS or a related condition; thus, the interventions are either wholly inappropriate or insufficiently adapted for this population. For example, an adolescent boy that was seen in an FASD clinic was described in a report from a social service agency as intentionally refusing to make use of the interventions that were being provided to him, which consisted primarily of cognitive behavioral therapy. Notably, this individual had also been diagnosed with conduct disorder. In fact, this individual did not meet criteria for conduct disorder, but rather had mild to moderate mental retardation and clearly met the criteria for FAS. Neither of these latter factors appeared to have been considered in his previous treatment planning, as his current level of functioning suggested that cognitive behavioral therapy was not the optimal form of intervention for him.

iv.) **Developmental history.** When obtaining a developmental history from a parent or caregiver, it is best to begin before pregnancy, by asking about the parents' expectations about the child and about parenthood—for example, "What did you imagine your lives would be like once the baby was born/adopted? What did you

imagine your child would be like?"—and the extent to which those expectations were or were not met. A review of the pregnancy, delivery, and perinatal period should include whether the pregnancy was planned, whether the couple had any difficulties becoming pregnant, and how far along the mother was when she learned she was pregnant. Any medical complications or stressors that occurred either prenatally or during the early postnatal period (e.g., threat of miscarriage, possibility of a genetic problem identified, insufficient growth, maternal depression, marital or relationship stress, hospitalization of baby and mother, time in the ICU, positive toxicology screening, removal from the home, poor parent bonding, disturbances in the infant-parent attachment relationship, etc.) should be noted. Mothers who consume alcohol during pregnancy often experience other accompanying risk factors, such as domestic violence (Martin, Beaumont, & Kupper, 2003), depression (Zuckerman, Amaro, Bauchner, & Cabral, 1989), or having a partner who is using alcohol (Wilsnack, Wilsnack, & Hiller-Sturmhofel, 1994).

For adoptive parents, it can be helpful to know how they came to the decision to adopt (including whether both parents were in agreement about the desire to adopt), and how the adoption process unfolded (including how long it took, whether there were any difficulties or complications encountered in the adoption process, what their expectations or fantasies were regarding what the adopted child would be like). Also of interest is their awareness of the child's prenatal history, including the child's possible prenatal exposure to alcohol and other teratogens. For foster children or children who were not adopted at birth, information about previous placements is critical to obtain (to the extent possible), including the number of placements, the nature of the placements (e.g., with a foster family, in an institution or orphanage), and the quality of care they received in such placements. For international adoptions, this information can be especially difficult to obtain, but it is quite important as such children might have traumatic histories from such previous placements or even from living on their own without any adult supervision or care (e.g., on the streets).

Following a better understanding of the individual's prenatal environment, and the circumstances under which the child was born (and adopted, if relevant), a standard developmental history is important to obtain. The child's major developmental milestones in language, socialization, self-help, and motor functioning should be queried. It is important to ask parents and caregivers at what specific ages these milestones were achieved, rather than just asking if they were achieved "on time," since many parents and caregivers might not know by what ages various milestones should be achieved.

v.) **Assessment of prenatal exposure to alcohol and other substances.** During this part of the interview, a thorough history regarding the individual's prenatal exposure to alcohol, as well as any other possible teratogens, is typically obtained. Clearly, the extent of information available regarding this aspect of the individual's history will vary depending on whether biological parents or adoptive or foster parents are being interviewed. Regardless, it is essential that the team takes a

nonjudgmental approach when obtaining this information and that team members are comfortable with asking detailed questions about prenatal alcohol and other substance use. Different measures and methodologies can be used to obtain this information (Floyd, O'Connor, Bertrand, & Sokol, 2006; Floyd, O'Connor, Sokol, Bertrand, & Cordero, 2005), but the following general recommendations are made when interviewing a biological mother:

- Questions about prenatal use of alcohol and other substances can be asked as part of a larger set of questions regarding the mother's health habits during pregnancy, such as exercise, nutrition, and prenatal care.
- Before asking about alcohol, nicotine, and illegal substance, ask about more benign substances first, such as coffee, tea, and caffeinated soda.
- Ask *how much* alcohol the mother consumed during pregnancy, rather than *if* the mother consumed alcohol during pregnancy.
- Ask about maternal alcohol use separately for three different time periods: prior to pregnancy, prior to pregnancy recognition, and following pregnancy recognition.
- Ask about different types of alcohol use separately (i.e., first inquire about beer, then wine, then hard liquor).
- Ask about both frequency (how often) and quantity (how much).
- Ask about both average/typical and maximum consumption (this approach can be used to inquire about other possible teratogens as well).
- Use physical props to assist the mother in estimating the amount of alcohol she consumed prior to and during her pregnancy. In a recent study by Barr and Streissguth (2001), a cut point of >7 drinks per week and >3 drinks per drinking occasion had 100% sensitivity and 83% specificity for diagnosis of FASD. In other studies, a cut point of 2 drinks per drinking occasion has been a statistically significant predictor of behavioral teratogenesis (O'Connor, et al., 1992; O'Connor, Kogan, & Findlay, 2002; Sood et al., 2001). However, any alcohol use during pregnancy should be carefully queried.

Obviously, questions about prenatal alcohol exposure would need to be modified for adoptive or foster parents or caregivers depending on how much information they have regarding the child's prenatal exposure. Although some adoptive and foster parents might have limited or no information about the child's prenatal exposure, they should still be queried about this information. Some adoptive and foster parents or caregivers might have first-hand knowledge of the child's history of exposure. For example, the caregiver might be a biological grandparent who directly observed the biological mother consuming alcohol during the pregnancy. In other cases, the adoptive or foster parents or caregivers might have received information that appears to be relatively reliable regarding the child's prenatal history. For example, they might have been told by the social worker that the child's biological mother acknowledged drinking during the pregnancy.

vi.) **Medical history.** A thorough medical history should include any major illnesses,

injuries, hospitalizations, immunizations, drug or food allergies, and most recent physical exam (including vision and hearing). The team should also consider the impact of the individual's medical status on the individual's development (i.e., have medical complications impeded development in other areas?), on their relationship with their parents or caregivers (i.e., a life-threatening illness might affect the parent-child attachment relationship), and on the parents' perception of the child (i.e., do parents view the child as "fragile"?).

As part of obtaining a thorough medical history, the team should inquire about medical issues that are more commonly seen in individuals with FASDs. Such issues might include cardiac problems, such as atrial and ventricular septal defects and stenosis of the pulmonary artery (Abel, 1990; Autti-Rämö et al., 2006; Cavieres & Smith, 2000), skeletal defects (Church et al., 1997), and dental problems (Autti-Rämö et al., 2006; Church et al., 1997). Ophthalmological problems are also well-documented in individuals with prenatal alcohol exposure, including strabismus; malformations or anomalies of the cornea, iris, lens, or retina; and reduced vision in one or both eyes (Autti-Rämö et al., 2006; Strömland, 2004; Strömland et al., 2005). Hearing problems are also not uncommon in alcohol-affected individuals. For example, Church et al. (1997) found an incidence of 27% of sensorineural hearing loss in a sample of 22 FAS patients, compared with an incidence of 1%–2% in the general pediatric population. In the same sample, these authors found that 77% of FAS patients had intermittent conductive hearing loss associated with recurrences of serous otitis media. Not surprisingly, other research has documented that children with FASDs are hospitalized more frequently than children without prenatal alcohol exposure (Kvigne et al., 2004). The increased incidence of a wide spectrum of medical issues observed in individuals with FASDs highlights the importance of evaluating whether there are any undiagnosed or untreated medical problems, and referring for further evaluation or treatment, as warranted.

The evaluation team should also obtain information about any medication the individual is currently being prescribed or has been prescribed in the past, particularly since individuals with FASDs are often receiving pharmacological treatment for comorbid psychiatric conditions. For example, through the lifespan, individuals with FASDs commonly present with clinical symptoms consistent with a diagnosis of ADHD. These individuals are most frequently diagnosed as the inattentive subtype of ADHD as defined by the DSM-IV (Kapp & O'Malley, 2001). The ADHD symptoms are particularly prevalent in childhood and early adolescence (Nanson and Hiscock, 1990; Streissguth, 1997) and the proposed link between FASD and ADHD is based on the premise that the teratogenic effects of ethanol exposure disturb the neurochemical and structural development of the fetal brain. For many children and adolescents with an FASD, these symptoms might be severe enough to warrant pharmacotherapy. Indeed, recent community and clinic-based surveys indicate that stimulants are commonly used in children with FASDs (O'Malley & Nanson, 2002). Despite common use, the empirical support for the efficacy of these medications in FASDs is limited. In the only published controlled study using psychostimulants, results were mixed, revealing some improvement in activity

level but little improvement in attention (Oesterheld et al., 1998; Snyder, Nanson, Snyder, & Block, 1997). As part of a UCLA study on social skills deficits in children with FASD (O'Connor et al., 2006), 100 children were examined for psychiatric diagnoses. Based on a structured diagnostic interview, 81% of children met criteria for a diagnosis of ADHD. At the baseline assessment, 40% of the children were on stimulants prescribed by community practitioners, with more than 50% having been on them for over a year. When symptoms of ADHD-associated problems were examined using parent report on the SNAP-IV, there were no differences on indices of inattention, hyperactivity, or oppositional defiant disorder between children on stimulant medication and those not on medication.

In addition, clinical data suggest that individuals with FASDs are often prescribed multiple psychiatric medications simultaneously, sometimes at fairly high doses. In a pilot study examining the prenatal alcohol exposure status of 163 consecutive patients admitted to the UCLA Child Psychiatric Inpatient Service, children with prenatal alcohol exposure averaged 2.56 medications on admission compared with an average 1.68 medications among unexposed children. Children with no prenatal alcohol exposure were more likely to be on no medication or on only one medication compared with exposed children who were more likely to be on two or more medications (O'Connor, 2008).

Furthermore, although there is a dearth of studies evaluating the efficacy of any psychiatric medications with children with prenatal alcohol exposure, clinical observations suggest that such individuals might have atypical responses to some psychiatric medications, making it challenging to design an appropriate medication regimen for them. Thus, a comprehensive assessment of any individual with prenatal alcohol exposure should include an evaluation by a child psychiatrist to determine if there is a need for psychotropic medication, and if so, what would be an optimal course of medication.

vii.) **Family medical and psychiatric history.** Information regarding both the immediate and extended family's medical and psychiatric history should be obtained. Obviously, a biological mother of a child with prenatal alcohol exposure should be queried about any history of alcohol or substance abuse or dependence, current abuse or dependence, and her own possible prenatal exposure. A number of reliable screening tools can be used to assess alcohol use, particularly high-risk alcohol use (see Floyd et al., 2006), and such measures might be helpful in augmenting information obtained during a clinical interview. For example, the TWEAK (Russell, 1994; Russell et al., 1994), AUDIT-C (Dawson, Grant, Stinson, & Zhou, 2005), and the T-ACE (Sokol, Martier, & Ager , 1989) have been recommended for women, whereas the CAGE (Mayfield, McLeod, & Hall, 1974) is often recommended for men, and the CRAFFT (Knight, Shrier, & Bravender, 1999) was designed for use with adolescents. The biological mother should also be asked about other possible co-morbid psychiatric conditions (e.g., depression, anxiety, ADHD) as these conditions also might be present in the child. Similar questions should be posed to the biological father if he is available. Parents should also be queried about the psychiatric and medical status of siblings, as well as any history of prenatal alcohol exposure among

siblings. Multiple children in the same family might be affected by prenatal alcohol exposure, and opportunities to identify siblings who might also benefit from an evaluation and intervention should not be missed. Previous research suggests that in families in which one child has already been born with FAS, subsequent children are at an approximately 800-fold increased risk of also being born with FAS (Abel, 1988). Of equal concern are recent findings that even among siblings without FAS, there is a significantly increased mortality rate due to infectious illness and sudden infant death syndrome (Burd, Klug, & Martsolf, 2004).

Foster and adoptive families might have less access to the medical and psychiatric history of the individual's biological family, but efforts to obtain this information through a review of records should be made. It is also important to inquire about the medical and psychiatric history of the foster or adoptive parents (and their extended family), as such history might still have an impact on the development and functioning of the alcohol-affected individual.

viii.) **Educational history and occupational functioning.** A comprehensive assessment should include information about the individual's experiences with the educational system, including details regarding his or her current and past school placements, special education services, and the parents' relationship with the individual's teachers and school systems. It is particularly important to assess the individual's perceptions of his or her experiences in school, as school is often the first place alcohol-affected individuals might come to perceive how different they are from same-age peers. In a study of secondary disabilities among adolescents and adults with FASDs, Streissguth and O'Malley (2000) found that 60% had "disrupted school experiences," which included being suspended, being expelled, or dropping out. Academic failures can be extremely demoralizing to individuals with FASDs. When not detected early, these failures persist and often become worse, and they might set alcohol-affected individuals on a course of quitting school, socializing with peers who exert negative influences on them, and becoming increasingly marginalized from the rest of society.

If the alcohol-affected individual is an adult, a thorough review of his or her employment history is important, as employment problems are common among individuals with FASDs (Streissguth & O'Malley, 2000). Has the individual had a stable employment history, or has he or she drifted from job to job or career to career? Has the individual been fired from jobs, and if so, why? Is he or she working in a position or field that is commensurate with his or her abilities and interests? What sorts of jobs has the individual enjoyed, or performed successfully? Is he or she happy with the current job or career, or does he or she need assistance in making changes in this area of his or her life? Executive function deficits in alcohol-affected individuals suggest that even if they have the cognitive capacity to carry out the individual tasks required in a particular job, they might still fail because they lack the organizational and planning skills required to perform successfully. For example, an alcohol-affected individual might be able to perform each individual task competently but have no ability to prioritize different tasks, and to the frustration of his or her supervisor, the individual assigns the least important tasks the greatest priority.

ix.) **Social functioning.** In addition to considering the alcohol-affected individual's functioning within his or her family, broader social functioning should also be taken into account when conducting an assessment. The team should ask about the individual's friendships and social networks, including the quality of these relationships, how much time the individual spends with friends, whether he or she experiences difficulties making or keeping friends, and whether the parents play an active role in helping the individual develop friendships. As noted earlier, individuals with FASDs often exhibit marked social impairment and might have great difficulty establishing and maintaining positive peer relationships. Such deficits in social functioning might escape the notice of parents, who often describe these children as being very friendly and outgoing but don't realize they might alienate peers with their intrusiveness, lack of awareness of appropriate boundaries, and difficulty anticipating the consequences of their own behavior. Although parents (and sometimes professionals) might view social skills deficits as of lower priority than difficulties in other domains, such as learning or academic problems, they should in fact be addressed. Poor peer relationship problems are associated with a significantly increased risk for delinquency and early withdrawal from school (Kupersmidt, Coie, & Dodge, 1990; Paetsch & Bertrand, 1997; Patterson, Forgatch, Yoerger, & Stoolmiller, 1998), outcomes to which individuals with FASDs are already vulnerable. Recent work suggests that an adapted, manualized social skills intervention can be effective for children with FASDs (Frankel, Paley, Marquardt, & O'Connor, 2006; Laugeson et al., 2007; O'Connor et al., 2006).

Information regarding relationships with romantic or sexual partners also should be obtained. Has the individual been able to establish meaningful, stable, satisfying relationships in this area of his or her life? Is the individual sexually active, and if so, is he or she using contraception both to prevent unplanned pregnancies and to protect against sexually transmitted diseases? Is sexual activity associated with alcohol or other substance use? Certainly, preventing additional generations of alcohol-exposed children should be a priority when working with individuals with FASDs.

x.) **Family structure, relationship, and dynamics.** As noted earlier, it is essential to consider the context in which the alcohol-affected individual is developing and functioning, and how he or she interacts with his or her environment. Consequently, the team should ask about the composition of the individual's family and the members of his or her household (which might or might not include the same people). The team should aim to understand the individual's relationships and interactions with important figures in his or her life, particularly with regard to how these relationships or interactions might optimize, or conversely, interfere with the individual's development and functioning.

Certainly, the quality of the parent-child relationship should be assessed, including how the parent might attempt to accommodate or offer additional support in light of the child's difficulties. Any factors that might compromise the parent's ability to provide instrumental or emotional caregiving or effective discipline should be noted, such as current parental alcohol/substance abuse, parental psychopathology,

and environmental stressors (e.g., financial problems, neighborhood crime). For biological mothers (and perhaps fathers), the team should assess if parental feelings of guilt or shame regarding the prenatal alcohol exposure might be impacting the quality of the parent-child relationship. For example, a biological mother who assumes all or most of the blame for her child's difficulties might find it difficult to set limits with her alcohol-affected child. In adoptive and foster families, parent-child relationships might be impacted if parents had different expectations or were unprepared for what their child would be like. Their sense of competence as parents might be undermined when their child continues to struggle despite all their efforts to provide a nurturing and supportive environment, and feelings of frustration or demoralization might become evident in their interactions with their children. Aspects of the alcohol-affected child's behavior or temperament also might make them more challenging to parent. For example, in a sample of middle-class biological mothers and their infants, O'Connor et al. (1992) found that higher levels of prenatal alcohol exposure were related to higher levels of infant negative affect, which in turn predicted less positive maternal behavior, which was associated with less secure infant attachment behavior. Among both biological and adoptive/foster parents of children with prenatal alcohol exposure, Paley and colleagues (2005; 2006) found that child behavior problems were associated with higher levels of parental stress. Such studies highlight the importance of assessing various aspects of the parent-child relationship, as they might represent an important focus of intervention.

Other relationships in the family should also be considered, including the relationship between parents (if there are two parents involved in the child's life), the child's relationship with any siblings, the parents' relationship with any other children they have, and the parents' relationship with their own parents. It is important to ascertain how the child and his or her difficulties have impacted the marital/inter-parental relationship, how any conflict or stress in the parents' relationship might be affecting the child, how the parents support, or alternatively, undermine one another in their parenting roles, how the child gets along with his or her siblings, how the parents perceive the individual relative to his or her siblings, and whether grandparents (or other extended family) are a source of stress or support to the parents and the child. In families of individuals with prenatal alcohol exposure, it is especially important to assess for issues such as one parent blaming the other for the child's difficulties (e.g., biological father being angry at the biological mother for drinking during the pregnancy), parents feeling overwhelmed if they are dealing with multiple children with prenatal alcohol exposure, or parents feeling guilty that they are neglecting their other unaffected children because they are having to devote so much time to the needs of the prenatally exposed child.

xi.) **Socioeconomic and cultural background.** The team should consider the ways in which socioeconomic and cultural factors might affect the family's views about and understanding of disabilities in general and fetal alcohol syndrome in particular. How are such factors relevant in terms of feelings of guilt or shame that the family might have in reaction to the diagnosis? How might such factors affect how the family views the etiology or cause of the individual's difficulties, even if they are

told the individual's difficulties are likely to be at least partly related to prenatal alcohol exposure? How have socioeconomic (e.g., poverty) and cultural (e.g., discrimination) factors potentially exacerbated the affected individual's difficulties and/or the family's ability to respond to those difficulties? Conversely, are there ways in which socioeconomic or cultural factors (e.g., certain beliefs or values, community resources) might have helped the individual and or the family to cope or adapt to the alcohol-affected individual's limitations?

It is also important to consider how cultural factors affect the family's willingness or comfort in seeking intervention for the individual and in accessing support or services for themselves. What barriers might prevent the family from accessing services in the larger community? It is well documented that significant disparities exist between whites and ethnic minorities in the United States in access to and the quality of medical care (Institute of Medicine, 2002) and mental health services (U.S. Dept. of Health and Human Services, 2001). It is important for the evaluation team to recognize that families who are from lower socioeconomic backgrounds and/or from ethnic minority backgrounds might not be treated in the same way by community agencies or the educational system as are families from higher socioeconomic backgrounds and/or from non-minority backgrounds. Consequently, the team might need to advocate for these families while working with them to develop strategies for accessing services so that they can become better advocates for themselves.

The team members must also consider how their own cultural background and beliefs might affect their views of and interactions with the family. For example, a team member might perceive an individual or the family as being uncooperative, when in fact they might simply be less comfortable being interviewed by someone from a different cultural background. Team members might have to confront their own unacknowledged stereotypes regarding groups that they believe are more or less likely to use or abuse alcohol. For example, in developing and implementing training materials on FASDs for medical students (Paley et al., 2006), a case was presented in which a young boy with undiagnosed FAS was brought into an emergency room by his biological mother, an affluent, well-educated, white attorney. When discussing the case, some of the students expressed surprise when the child's history of prenatal alcohol exposure was revealed, with some commenting that they didn't expect a woman from that kind of background to drink during her pregnancy. Perhaps such attitudes might be more common among students or less experienced professionals, but even more seasoned team members must be vigilant for their own unacknowledged biases and stereotypes when working in this area. Additionally, team members might sometimes make assumptions about an individual or family from a particular subgroup based on their general beliefs about that subgroup's broader culture. However, such general beliefs might or might not be relevant for that particular subgroup or that particular individual or family. For example, members of the team might have certain beliefs about the "Hispanic" or "Latino" culture without appreciating differences among Mexican, Puerto Rican, and Cuban subgroups.

It is unrealistic to expect that the team will have expertise in every cultural group and subgroup. Nonetheless, it is essential for the team to at least be aware of the myriad ways in which socioeconomic and cultural factors might affect the perceptions, interactions, and experiences of the affected individual, his or her family, and the team members themselves when conducting an evaluation. Moreover, team members should consider consulting with colleagues who have expertise in working with families from particular backgrounds when needed.

xii.) **Strengths and resources.** In evaluating individuals with FASDs (or anyone for that matter), it is important to ask not only about areas of impairment that might benefit from intervention, but also about the strengths of the individual and his or her family, as well as any resources of which they might avail themselves. Inquiring about these areas is an important part of the evaluation process, particularly for parents/caregivers who are so used to focusing on their child's deficits or weaknesses. Such questions can remind parents of their child's positive qualities and encourage them to once again view their child in a more holistic way, rather than just as a child with problems. Reviewing the individual's and the family's strengths during feedback can provide an important counterbalance to much of the information provided during feedback that will likely focus on domains in which the individual or family needs help.

Identifying strengths can also be extremely useful when designing a treatment plan for the individual, as these strengths can be capitalized on during intervention. For example, during an evaluation, it became apparent that a young patient had particularly strong artistic abilities. One of the evaluation team's recommendations was for the parents to find ways to encourage and foster those artistic talents. The parents subsequently enrolled the child in some art classes, and the child, who had previously been quite withdrawn and demoralized from having difficulties in so many other domains, seemed to flourish from having success in a particular area of his life. Although the child certainly required other interventions to address various areas of deficit, it was clearly beneficial to both the child and the parents to also focus on something in which the child could excel.

Similarly, it would be helpful to note whether there are resources or systems available in the individual's own community that can be mobilized to provide additional support. For example, in some communities, individuals with disabilities are especially likely to be embraced or even protected within that community. The evaluation team might wish to work with other community members to help them develop plans for how to accommodate the alcohol-affected individual and enhance that individual's opportunities for progress and growth.

c. *Clinical interview with alcohol-exposed individual.* In some instances, it might be appropriate to conduct a clinical interview with the alcohol-affected individual, depending on his or her age and developmental level. For these individuals, the interview outlined previously could be adapted, taking into account the individual's capacity to understand and respond to the questions. Such an interview might focus on the individual's understanding of why he or she has come in for an assessment, and what he or she hopes to learn from the assessment. Depending on age and developmental level, it might be appropriate to discuss

the individual's understanding of prenatal alcohol exposure and fetal alcohol syndrome, and how he or she perceives prenatal alcohol exposure to have affected his or her life.

The individual might be asked about what he or she perceives to be his or her greatest areas of difficulty, as parents or caregivers might not always be aware of all the challenges experienced by an alcohol-exposed individual. For example, parents or caregivers often don't recognize the significant peer relationship problems experienced by those with FASDs, instead believing that because their child is friendly and outgoing, he or she must have an abundance of friends. However, when these individuals are queried directly, they might acknowledge having no or few friends, being actively rejected by others (e.g., "no one likes me"), and feeling very lonely. Older children, adolescents, and adults might also be able to provide unique insights regarding the less salient, but equally detrimental, disabilities associated with prenatal alcohol exposure (e.g., depression), as their parents/caregivers might be more focused on issues that are more problematic for others (e.g., impulsivity).

2. **Behavioral observations.** In a child with suspected or known prenatal alcohol exposure, behavioral observations should include a description of multiple aspects of the child's behavior, both positive and negative. The domains noted below would be relevant for any child, but many are especially important to note in an alcohol-exposed child. The Fetal Alcohol Behavior Scale (FABS; Streissguth, Bookstein, Barr, Press, & Sampson, 1998), a rating scale that parents typically complete, can also be used as a guide with regards to specific behaviors that are often seen in children with prenatal alcohol exposure.

   a. *Appearance*. Does the individual appear small for or younger than his or her chronological age? Does he or she have any obvious dysmorphology or physical anomalies? Are there any visible injuries (e.g., bumps, bruises) that might be a function of either the child's impulsivity or poor balance or coordination?

   b. *Activity level*. Is the child excessively active, squirmy, fidgety, even beyond what would be expected for his or her developmental level?

   c. *Attentional abilities*. Is the child's ability to focus consistent with his or her age and/or developmental level? Is he or she easily distracted by extraneous stimuli, such as noises in the hallway or outside traffic?

   d. *Impulsivity*. Is the child's level of impulsivity consistent with his or her age and/or developmental level? Does he or she seem to consider consequences before acting? Does he or she engage in dangerous or risky behavior (e.g., trying to climb up to or jump from high places)?

   e. *Social interaction/relatedness*. Is the child socially indiscriminant—that is, does he or she easily approach and engage strangers without any hesitation or wariness? How does the child interact with peers? Is he or she overly intrusive or too physical with other children?

   f. *Affect and mood*. What type(s) of affect does the child exhibit? Does his or her affect change predictably or without warning and without any clear precipitants? Does the child report a particular mood state? Is the child able to describe his internal mood states?

g. *Emotional regulation*. What is the child's ability to manage his or her own emotional states? Does the child seek comfort from others when distressed? Does he or she preferentially seek comfort from parents/caregivers or is he or she just as likely to seek out the examiner? How does the child respond to others' efforts to soothe him or her?

h. *Motivation, persistence, response to frustration*. How does the child respond to success or failure? How does the child respond to frustration? Does he or she persist in the face of a challenging task, or alternatively, give up easily or throw a tantrum ?

i. *Response to consequences*. Does the child appear motivated by positive reinforcement? Does the child appear to understand the link between behavior and consequences (e.g., contingencies)?

j. *Play*. What type of play does the child engage in (functional, symbolic or imaginative)? Is it appropriate to his or her development level? Is the child's play perseverative (focuses only on one object or one theme), or is it rich, elaborative, varied? Does the child attempt to engage others in play, or does he or she seem to prefer playing alone?

k. *Speech and language*. Is the child's articulation consistent with his developmental level? Does he or she appear to have some phonological difficulties? Does the child exhibit difficulties in expressive language? Is the child quite talkative, but upon closer examination, does not say much that is meaningful? How well is the child able to express ideas clearly? Does the child have difficulty relating events or telling a story in a logical, coherent manner? Does the child appear to have difficulties with receptive language? Does he or she understand simple questions? Does he or she understand and respond to basic and multistep instructions? How does the child manage the social aspects of communication (e.g., turn-taking, eye contact, appropriate volume).

l. *Motor functioning*. Does the child appear to have difficulty with fine or gross motor skills, balance, or coordination?

Older individuals should also be observed with regard to the following:

m. *Judgment*. Does the individual make thoughtful decisions and is he or she able to articulate the basis of their decisions? Is he or she able to plan out his or her actions and anticipate the consequences of those actions?

n. *Insight*. Does the individual seem to understand the motivations and feelings that drive his or her behavior? Does he or she seem aware of his or her own internal states? Does he or she seem to understand his or her impact on others?

o. *Problem-solving abilities*. Is he or she able to solve problems hypothetically, as opposed to relying largely on trial and error? Does he or she keep trying the same solutions over and over even when they don't work?

p. *Abstract thinking*. Does the individual appear to understand metaphors, idioms, figurative language? Does he or she appear to understand sarcasm, jokes, or teasing?

q. *Self-image*. Is the individual able to recognize his or her own strengths or positive qualities or does he or she appear focused on his or her weaknesses? Does he or she appear demoralized by the difficulties he or she has encountered in the various domains of his or her life or does he or she remain optimistic that he or she can make positive changes in his or her life?

3. **Standardized testing.** When evaluating individuals with prenatal alcohol exposure, a comprehensive battery of tests that includes measures of cognitive, neuropsychological, academic, adaptive, behavioral, social, and emotional functioning is optimal. Standardized measures might include tests that are directly administered to the patient (e.g., intelligence tests, tests of executive function), and rating scales or interviews that are administered to parents, other caregivers, teachers, other professionals, and perhaps to the patient, depending on his or her chronological and developmental age.

   For alcohol-affected individuals, one should remember that an individual with an IQ in the normal range (which many individuals with FASDs will have) might still have significant impairments. Streissguth and O'Malley (2000) have found that a diagnosis of FAS, as opposed to a diagnosis of another alcohol related condition, such as FAE, is a protective factor against secondary disabilities. One possible reason for this is that individuals without full-blown FAS are less likely to be recognized in need of services, perhaps because they are more likely to have normal IQs. However, alcohol-exposed individuals with and without full-blown FAS show similar deficits in executive functioning (Connor et al., 2000; Kodituwakku et al., 2001; Mattson et al., 1999). Indeed, a number of researchers have found that executive functioning in individuals with FASDs is lower than what would be expected based on their IQs (Connor et al., 2000). Given these discrepancies, tests of intelligence are not thought to adequately capture the full extent of cognitive impairment that might occur because of alcohol exposure in utero. For this reason, a comprehensive assessment of the individual's strengths and weaknesses is required in order to provide useful information to guide intervention planning. When evaluating individuals with prenatal alcohol exposure, evaluation should include overall measures of cognitive functioning in addition to achievement testing, neuropsychological assessment (including measures of executive function), and measures of adaptive, behavioral, emotional, and social functioning. Additionally, speech and language testing, and occupational and/or physical therapy evaluations might be conducted, or patients might be referred for such assessments if the relevant professionals are not part of the evaluation team.

   The assessment battery should include measures that have been standardized and normed on a diverse sample. Testing results should be interpreted in light of relevant cultural factors, language issues, and environmental experiences.

   The following list describes tests that research and/or clinical experience have shown to be useful when evaluating individuals for FASDs. It is, however, by no means exhaustive. These tests are also presented in Table 5.1, organized by domain assessed and age range covered. Other researchers have also provided helpful recommendations regarding tests that might be particularly useful for this population (Canadian Pediatric Society, 2002; Chudley et al., 2006; Olson & Clarren, 1996). Of course, the particular battery selected for each patient should be based on the referral questions, the possible areas of strength and weakness that

have emerged from the clinical interview, and assessment that have been done in previous evaluations.

a. *Antisocial Process Screening Device* (ASPD; Frick & Hare, 2001). Formerly known as the Psychopathy Screening Device, the ASPD is a questionnaire to be filled out by a child's parent and teacher. It is administered for children aged 6–13 years; an older adolescent form, The Psychopathy Checklist: Youth Version, is also available. The ASPD measures precursors to antisocial behaviors and, importantly, can distinguish if such behaviors are due to impulsivity as opposed to narcissistic or callous/unemotional (e.g., lack of guilt or empathy) character traits. The prediction is that children with prenatal alcohol exposure will have behaviors more closely associated with impulsivity. Higher scores on these scales indicate greater indication of having those traits.

b. *Bayley Scales of Infant Development – 3rd Edition* (BSID-III; Bayley, 2005). The BSID–III is an early childhood standardized assessment of cognitive, language, and motor development, as well as adaptive and socioemotional functioning. It is for children aged 1–42 months of age. The Cognitive, Language, and Motor scales are administered by a clinician, and the Adaptive and Social Emotional domains are assessed through parent questionnaires.

c. *Beery-Buktenica Developmental Test of Visual Motor Integration – 5th Edition* (Beery VMI-5; Beery & Buktenica, 1997). The Beery VMI-5 is a widely used instrument that assesses the integration of the visual and motor system. This test requires the examinee to copy shapes of increasing levels of difficulty. This test can indicate whether a child is having difficulty with visual spatial and graphomotor functioning. The Beery VMI-5 is normed for ages 2–18 years. Should deficits arise, separate visual and motor testing from this instrument should be given to parse out where the difficulties lie.

d. *Behavior Rating Inventory of Executive Function: Parent and Teacher Forms* (BRIEF; Gioia, Isquith, Guy, & Kenworthy, 2000). The BRIEF is a questionnaire filled out by parents and teachers to obtain information about a child's executive functioning in daily activities. This information, in combination with that obtained in structured testing situations, provides a comprehensive assessment from which one can infer how deficits and strengths might impact the child's day-to-day life. This questionnaire assesses the child's functioning in executive domains such as inhibition, shifting cognitive set, emotional control, initiating behavior, working memory, planning and organizing behavior, organizing materials, and monitoring of behavior. This test has separate norms for boys and girls aged 5–18 years.

e. *Beck Depression Inventory – II* (BDI-II; Beck, Steer, & Brown, 1996). The BDI-II is a self-report measure of depressive symptomatology in adults. The BDI-II demonstrates good internal consistency (0.92–0.93) and test-retest reliability (0.92), and it correlates well with other measures of depression (0.68–0.71).

f. *Boston Naming Test – 2nd edition* (BNT; Kaplan, Goodglass, & Weintraub, 1983). The BNT is a confrontational naming test requiring individuals to correctly label 60 visual presented stimuli.

g. *Brief Symptom Inventory* (BSI; Derogatis, 1993). The BSI is a 53-item self-report measure, assessing a broad array of psychopathology and somatic complaints in adults. It is comprised of nine primary symptom dimensions: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and pscychoticism. The BSI also yields three global indices: Global Severity Index, Positive Symptom Distress Index, and Positive Symptom Total. Test-retest reliability coefficients range from 0.68 (somatization) to 0.91 (phobic anxiety) and internal consistency alphas range from 0.71 (psychoticism) to 0.85 (depression) (Piersma, Boes, & Reaume, 1994). The BSI also correlates significantly with other measures of psychopathology (Morlan & Tan, 1998), providing evidence for its concurrent validity.

h. *California Verbal Learning Test – Children's Version* (CVLT-C; Delis, Kramer, Kaplan, & Ober, 1994). The CVLT-C is a non-contextual verbal learning and memory task designed for children aged 5–16 years. The CVLT-C requires examinees to learn a "shopping list" over five learning trials. Their short and long delayed memory for the list is then assessed and semantic cued recall trials are provided following each free recall trial to aid in retrieval. Therefore, difficulties in learning or acquiring information as opposed to memory deficits might be parsed out. Finally, a recognition test trial concludes the assessment.

i. *California Verbal Learning Test – 2nd Edition* (CVLT-II; Delis, Kramer, Kaplan, & Ober, 2000). Like the CVLT-C, the CVLT-II is a non-contextual verbal learning and memory test. This test is normed for ages 16–89 years. The CVLT-II involves a 16-word list read over five learning trials. This adult counterpart to the CVLT-C involves recall after the five learning trials, free recall following both short and long delay periods, semantic cued recall, and recognition testing. In addition, the CVLT-II has a forced choice recognition task.

j. *Child Behavior Checklist, Caregiver-Teacher Report Form, Teacher Report Form, and Youth Self-Report* (CBCL, C-TRF, TRF, & YSR; Achenbach & Rescorla, 2001). The CBCL is a questionnaire filled out by the parent to evaluate the presence and frequency (e.g., not at all, sometimes, often) of various problem behaviors that might be seen in children. It evaluates the presence of any internalizing (e.g., depression) or externalizing (e.g., hyperactivity) behaviors. There are separate parent report forms for children 18 months–5 years and 6–18 years. There are analog forms that can be completed by caregivers or teachers for children 18 months–5 years (C-TRF) and by teachers for children aged 6–18 years (TRF). In addition, the YSR is a self-report measure for children aged 11–18 years. The CBCL, C-TRF, TRF, and YSR indicate the clinical significance of internalizing, externalizing, and total behavior problems. All forms are recommended to compare behavior across settings and raters.

k. *Children's Color Trails Test* (CCTT; Llorente, Williams, Satz, & D'Elia, 2003). The CCTT is a measure of visual sequencing, sustained attention, processing speed, and cognitive flexibility. The first form of the test requires sequencing numbers; the second form requires sequencing numbers while concurrently switching between those with a pink or yellow background. The CCTT reduces the reliance on language compared with other traditional trail-making tests. This test is normed for children aged 8–16 years.

l. *Children's Depression Inventory* (CDI; Kovacs, 1992). The CDI is a measure of depressive symptomatology administered to school-age children and adolescents aged 7–17 years. On this questionnaire, examinees choose which of three sentences statements best describes how they have been feeling in the past 2 weeks. This test provides indices of Negative Mood, Interpersonal Problems, Ineffectiveness, Anhedonia, and Negative Self-Esteem in addition to a Total Depression Score.

m. *Children's Memory Scale: Stories, Dot Locations, Family Pictures subtests* (CMS; Cohen, 1997). The CMS is a comprehensive learning and memory test normed for children aged 5–16 years. The Stories subtest measures contextual verbal memory through the immediate and delayed retelling of two very short stories. The Dot Locations and Family Pictures subtests are measures of visual learning and memory out of context and within context, respectively. The former test requires learning and recalling the location of dots on a grid, while the latter test requires recalling the location and action of family members within one of four illustrated vignettes. Combined with the CVLT-C, these learning and memory tests provide indices of the child's or adolescent's verbal and visual learning and memory both within and out of context.

n. *Clinical Evaluation of Language Fundamentals – 4th edition* (CELF-4; Semel, Wiig, & Secord, 2003). The CELF-4 is used to identify language skill in individuals 5–21 years of age. This measure yields a Core Language Score (based on four subtests), as well as Receptive Language and Expressive Language Composites.

o. *Conners' Rating Scales – Revised* (CRS-R; Conners, 2000). The CRS-R is a questionnaire administered to both the child's parent and teacher to assess significant problem behaviors. It identifies children who might meet criteria for ADHD as defined by the DSM-IV with additional individual scales assessing oppositionality, inattention, hyperactivity, anxious/shy behaviors, perfectionism, social problems, or psychosomatic symptoms. This measure is normed for children and adolescents aged 3–17 years.

p. *Continuous Performance Test – II* (CPT-II; Conners & MHS Staff, 2000). The CPT-II is a computerized test designed to assess vigilance (i.e., sustained attention) and impulse control. This measure can be used with individuals 6 years old through adulthood. For younger children, the Kiddie CPT (K-CPT; Conners & MHS Staff, 2001) can be used. Test-retest reliability for the Omission Errors score (which assesses vigilance) is 0.84 and for the Commission Errors score (which assesses impulse control) is 0.65. The CPT-II also distinguishes effectively between ADHD groups and non-clinical groups, as well as ADHD groups and psychiatric controls (Conners & MHS Staff, 2000).

q. *Delis-Kaplan Executive Function System: Twenty Questions Test, Color Word Interference Test; Verbal Fluency, Tower subtests* (D-KEFS; Delis, Kaplan, & Kramer, 2001). The D-KEFS offers a comprehensive evaluation of higher cognitive or executive functions that are required to engage in effective goal-directed behaviors. Selected subtests can be chosen which might be particularly appropriate for children with prenatal exposure to alcohol. For example, the Twenty Questions test provides a measure of concept formation and problem-solving ability. From an array of colorful objects, animals, and plants, the examinee must guess the item that the examiner is thinking of in as few trials

as possible. The Color Word Interference test is a variant of the traditional Stroop test (Golden & Freshwater, 2002). It measures cognitive inhibition by having the examinee name the color ink that a discrepant color word is printed in. The Verbal Fluency subtest involves rapid unique word generation under time constraints. This test measures both phonemic (i.e., beginning with a specific letter) and category (i.e., belonging to a specific category) fluency. This test also involves a switching condition to evaluate flexibility in thinking. These selected subtests are administered to individuals 8 years through late adulthood. The Tower subtest involves moving colored discs of increasing size across three pegs to match a model. However, the examinee must adhere to strict rules that engage their planning ability, working memory, and problem-solving skills.

r. *Fetal Alcohol Behavior Scale* (FABS; Streissguth et al., 1998). The FABS is a questionnaire filled out by the parents or caregivers of individuals with prenatal alcohol exposure. It is normed for individuals aged 2–51 years. This questionnaire involves assessing behaviors that are often seen in those with prenatal alcohol exposure in the categories of communication and speech, personal manner, emotions, motor skills and activities, social skills and interactions, academic/work performance, and bodily and physiological functions.

s. *Finger Tapping Test* (FTT; Halstead, 1947). The FTT is a component of the Halstead Reitan Neuropsychological Test Battery (Reitan, 1979). This test is a measure of fine motor speed and requires the child to tap a key on a board as rapidly as possible with their index finger only. Normative data and administration instructions are available for individuals aged 5 through adulthood (Baron, 2004; Spreen & Strauss, 1998).

t. *Grooved Pegboard Test* (GPT; Reitan & Davison, 1974). The GPT is commonly used as part of the extended Halstead Reitan Neuropsychological Test Battery (Reitan, 1979). This test measures fine motor dexterity and speed. It requires the child to manipulate and place 25 keyhole-shaped pegs in a board as rapidly as possible. Normative data and administration instructions are available for individuals aged 5–14 years (Baron, 2004).

u. *NEPSY – Second Edition* (NEPSY II; Korkman, Kirk, & Kemp, 2007). The NEPSY II is a comprehensive neuropsychological test battery designed to assess specific functions in six domains: executive function and attention, language, memory and learning, sensorimotor functioning, visuospatial processing, and social perception. Although a complete battery can be administered, the NEPSY II allows for flexible administration and encourages choosing selected subtests as appropriate for the child being assessed. Unlike many neuropsychological measures, the NEPSY II offers normative data for children as young as 3 and as old as 16 years of age.

v. *NIMH Diagnostic Interview Schedule for Children – Version IV* (NIMH DISC-IV; Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000). The computerized version of the NIMH DISC-IV, the C-DISC 4.0, is a highly structured diagnostic interview designed to assess psychiatric disorders in children and adolescents. The parent version of the DISC-IV asks parents questions about their children aged 6–17 years. The DISC-IV assesses the presence of diagnostic symptoms occurring within both the past 12 months and the past 4 weeks. It is recommended for individuals with prenatal alcohol exposure because the majority present with co-morbid psychiatric disorders. The DISC-IV is expected to take approximately 60 minutes for the parent to complete.

w. *Pictorial Depression Scale* (PDS; O'Connor & Kasari, 2000). The PDS is used to assess depressive symptomatology in children as young as 4 years of age and for older children for whom the CDI is too difficult. The PDS is a 23-item scale that is adapted from the CDI. This test involves showing children two identical side-by-side stick figure children with neutral expressions who are the same sex as the child being tested. The children are to point to the child who is most like them when two statements are read about each "child" (e.g., this child feels sad/ this child does not feel sad).

x. *Preschool Language Scale – 4th edition* (PLS-4; Zimmerman, Steiner, & Pond, 2002). The PLS-4 assesses receptive and expressive language in young children. This measure yields scores in three domains: total language, auditory comprehension, and expressive language. It is normed for children from birth through 6 years, 11 months of age. It also includes a Caregiver Questionnaire that allows parents to report on the child's communication skills at home.

y. *Structured Clinical Interview for DSM-IV™ Axis I Disorders, Clinician Version (*SCID-I; First, Spitzer, Gibbon, & Williams, 1996); *Structured Clinical Interview for DSM-IV™ Axis II Disorders* (SCID-II; First, Spitzer, Gibbon, & Williams, 1997). The SCID-I is a structured diagnostic interview that assesses DSM-IV™ Axis I disorders in adults. Six modules are covered, including mood episodes, psychotic symptoms, psychotic disorders, mood disorders, substance use disorders, and anxiety, adjustment, and other disorders. The SCID-II covers DSM-IV™ Axis II personality disorders. Good reliability and validity have been demonstrated for both the SCID-I and SCID-II (Basco et al., 2000; Maffei et al., 1997; Skodol, Rosnick, Kellman, Oldham, & Hyler, 1988; Zanarini et al., 2000).

z. *Test of Language Competence – Expanded Edition* (TLC-Expanded; Wiig & Secord, 1989). The TLC-Expanded assesses higher-level language functioning. This measure is normed for children aged 5–18 years, with Level I for children 5–9 years old, and Level II for children 10–18 years old. Subtests include Ambiguous Sentences, Listening Comprehension: Making Inferences, Oral Expression: Recreating Speech Acts, and Figurative Language. Composite scores are yielded in three domains: Overall Age Equivalent Score, Listening Comprehension, and Oral Expression.

aa. *Vineland Adaptive Behavior Scales – 2nd edition* (Vineland II; Sparrow, Cicchetti, & Balla, 2005). The Vineland-II Survey Interview and Parent/Caregiving Rating Form are used to assess an individual's competencies in day-to-day functions and are normed for ages 0 months through 90 years. Three domains are measured: Communication Skills, Daily Living Skills, and Socialization Skills. For children under age 6, Motor Skills are also assessed. The Survey Interview is administered to parents or caregivers by a clinician, and the Parent/Caregiving Rating Form is a rating scale completed independently by parents or caregivers. The Vineland-II allows clinicians to obtain information on how the child is functioning outside of a structured clinical setting and provides information about the extent (regularly, occasionally, or seldom) to which the individual performs various tasks of adaptive functioning.

ab. *The Wechsler Individual Achievement Test – 2nd Edition* (WIAT-II; Wechsler, 2001). The WIAT-II is a comprehensive evaluation of academic skills including reading, spelling, and

arithmetic. Importantly, these areas provide information on all of the areas required by the Individuals with Disabilities Education Act (IDEA). This measure is normed for children as young as 4 years and extends through adulthood. One can elect to administer the entire battery or select specific subtests for a more focused assessment.

ac. *Wechsler Intelligence Scale for Children – 3rd Edition as a Process Instrument: Digit Span and Spatial Span Subtests* (WISC-III PI; Kaplan, Fein, Kramer, Delis, & Morris, 1999). The WISC-III PI Digit Span subtest assesses immediate auditory attention and auditory working memory. In this subtest, the examinee is required to recall strings of numbers of increasing length. In the forward condition, the examinee recalls the string in the same order they were presented; in the backward condition, the examinee must recall the string of numbers in reverse order. The WISC-III PI Spatial Span subtest is a visual analogue to the WISC-III Digit Span subtest. It involves immediate visual attention and visual working memory. The examinee is required to immediately recall block locations that the examinee touched on a board. They first recall locations forward and then backward. Both subtests provide separate norms for the forward and backward condition in addition to a total score. These tests are normed for children aged 6–16 years.

ad. *Wechsler Memory Scale – 3rd Edition* (WMS-III; Wechsler, 1997a). The WMS-III assesses multiple domains of memory for individuals aged 16–89 years of age. This measure yields eight Primary Index scores, including Auditory Immediate, Visual Immediate, Immediate Memory, Auditory Delayed, Visual Delayed, Auditory Recognition Delayed, General Memory, and Working Memory, as well as four Auditory Process Composites. The WMS-III has good internal consistency (mean for subtests = 0.81; mean for indexes = 0.87) and good test-retest reliability (0.62–0.82). It also demonstrates good convergent and divergent validity (Wechsler, 1997a).

ae. *Wechsler Preschool and Primary Scale of Intelligence – 3rd Edition* (WPPSI-III; Wechsler, 2002); *Wechsler Intelligence Scale for Children – 4th Edition* (WISC-IV; Wechsler, 2003); *Wechsler Adult Intelligence Scale – 3rd Edition* (WAIS-III; Wechsler, 1997b). These scales are assessments of overall cognitive ability or intelligence. The WPPSI-III is normed for children aged 2 years, 6 months to 7 years, 3 months. The WISC-IV is normed for children and adolescents aged 7–17 years, and the WAIS-III is normed for adults aged 16–89 years. All three measures yield a Full Scale IQ score or overall estimate of cognitive ability that is the composite of various index scores.

af. *Wisconsin Card Sorting Test* (WCST; Heaton, Chelune, Talley, Kay, & Curtiss, 1993). The WCST is a measure of problem solving and cognitive flexibility. The examinee sorts cards and solves problems, switching his or her sorting principle according to an unspoken rule. Results indicate how the examinee solves problems, if he or she is flexible in thinking, and how he or she responds to examiner feedback. This test has normative date for ages 6 years, 6 months through adulthood, although it works best with children aged 8 years and older. A computerized version of this test is also available.

Table 5.1. Suggested Assessment Measures for Individuals With FASDs

Age	History	Physical	Visual Spatial/ Fine Motor	Memory	Cognitive	Executive	Attention	Behavioral/ Emotional/ Social	Language	Achieve-ment	Adaptive
Infancy–Toddlerhood (0–3 Years)	▪ Parent Interview ▪ Records Review	Dysmorph-ology & Medical Exam	▪ BSID-III ▪ Beery VMI-5	▪ BSID-III	▪ BSID-III	▪ N/A	▪ BSID-III	▪ CBCL (≥1.5 yrs) & C-TRF ▪ FABS (≥2 yrs	▪ BSID-III ▪ PLS-4	N/A	Vineland II
Preschool (3–4 Years)	▪ Parent Interview ▪ Records Review	Dysmorph-ology & Medical Exam	▪ Beery VMI-5 ▪ NEPSY II	▪ NEPSY II	▪ BSID-III OR ▪ WPPSI-III	▪ NEPSY II	▪ NEPSY II ▪ CRS-R ▪ K-CPT	▪ CBCL & C-TRF ▪ CRS-R ▪ PDS (≥4 yrs) ▪ FABS	▪ BSID-III (≤3.5 yrs) ▪ PLS-4 ▪ NEPSY II	WIAT-II (≥4 yrs)	Vineland II
5–12 years	▪ Parent Interview ▪ Patient Interview (as appropriate) ▪ Records Review	Dysmorph-ology & Medical Exam	▪ Beery VMI-5 ▪ NEPSY II ▪ FTT ▪ GPT	▪ CMS ▪ CVLT-C ▪ WISC-III PI Spatial Span and Digit Span (≥6 yrs)	▪ WPPSI-III OR ▪ WISC-IV	▪ BRIEF ▪ CCTT (≥8 yrs) ▪ D-KEFS (≥8 yrs) ▪ NEPSY II ▪ WCST (≥8 yrs)	▪ NEPSY II ▪ CRS-R ▪ K-CPT or CPT-II ▪ WISC-III PI Spatial Span and Digit Span	▪ CBCL & TRF (YSR ≥11 yrs) ▪ CRS-R ▪ PDS (4–8 yrs) or CDI (≥8 yrs) ▪ FABS ▪ ASPD ▪ NIMH DISC-IV	▪ CELF-4 (≥6 yrs) ▪ TLC ▪ NEPSY II	WIAT II	Vineland II
Adolescence	▪ Parent Interview ▪ Patient Interview ▪ Records Review	Dysmorph-ology & Medical Exam	▪ Beery VMI-5 ▪ FTT ▪ GPT (≤14 yrs)	▪ CMS (≤16 yrs) ▪ CVLT-C or CVLT-II ▪ WISC-III PI Spatial Span and Digit Span	▪ WISC-IV OR ▪ WAIS III	▪ BRIEF ▪ CCTT (≤16 yrs) ▪ D-KEFS ▪ WCST	▪ CRS-R ▪ CPT-II ▪ WISC-III PI Spatial Span and Digit Span	▪ CBCL, TRF & YSR ▪ CRS-R ▪ CDI ▪ FABS ▪ NIMH DISC-IV	▪ CELF-4 ▪ TLC ▪ D-KEFS Verbal Fluency	WIAT II	Vineland II
Adulthood	▪ Patient Interview ▪ Parent Interview (if possible) ▪ Records Review	Dysmorph-ology & Medical Exam	▪ FTT ▪ WAIS III Block Design	▪ WMS-III ▪ CVLT-II	▪ WAIS III	▪ BRIEF ▪ D-KEFS ▪ WCST	▪ CPT-II	▪ FABS ▪ BDI II ▪ BSI ▪ SCID I & II	▪ D-KEFS Verbal Fluency ▪ Boston Naming Test	WIAT II	Vineland II

ASPD: Antisocial Process Screening Device; BDI-II: Beck Depression Inventory – II; Beery VMI-5: Beery-Buktenica Developmental Test of Visual Motor Integration – 5th Edition; BRIEF: Behavior Rating Inventory of Executive Function: Parent and Teacher Forms; BSI: Brief Symptom Inventory; BSID-III: Bayley Scales of Infant Development – 3rd Edition; CBCL: Child Behavior Checklist; CCTT: Children's Color Trails Test; CDI: Children's Depression Inventory; CELF-4: Clinical Evaluation of Language Fundamentals, 4th Edition; CMS: Children's Memory Scale: Stories, Dot Locations, Family Pictures Subtests; CPT-II: Continuous Performance Test – II; CRS-R: Conners' Rating Scales – Revised; C-TRF: Caregiver-Teacher Report Form; CVLT-C: California Verbal Learning Test – Children's Version; CVLT-II: California Verbal Learning Test – 2nd Edition; D-KEFS: Delis-Kaplan Executive Function System: Twenty Questions Test, Color Word Interference Test, Verbal Fluency, Tower subtests; FABS: Fetal Alcohol Behavior Scale; FTT: Finger Tapping Test; GPT: Grooved Pegboard Test; K-CPT: Kiddie Continuous Performance Test; Nepsy II: NEPSY – 2nd Edition; NIMH DISC-IV: NIMH Diagnostic Interview Schedule for Children, Version IV; PDS: Pictorial Depression Scale; PLS-4: Preschool Language Scale – 4th Edition; SCID I & II: Structured Clinical Interview for DSM-IV™ Axis I Disorders, Clinician Version & for Axis II Disorders; TLC: Test of Language Competence – Expanded Edition; TRF: Teacher Report Form; Vineland II: Vineland Adaptive Behavior Scales, 2nd Edition; WAIS III: Wechsler Adult Intelligence Scale - 3rd edition; WISC IV: Wechsler Intelligence Scale for Children - 4th edition; WCST: Wisconsin Card Sorting Test; WIAT-II: Wechsler Individual Achievement Test – 2nd Edition; WISC-III PI: Wechsler Intelligence Scale for Children – 3rd Edition as a Process Instrument: Digit Span and Spatial Span Subtests; WMS-III: Wechsler Memory Scale – 3rd Edition; WPPSI-III: Wechsler Preschool and Primary Scale of Intelligence – 3rd Edition; YSR: Youth Self-Report.

4. **Dysmorphology exam.** As part of a comprehensive evaluation, the individual should be assessed for the physical features associated with prenatal alcohol exposure. Such assessments are typically conducted by a dysmorphologist or pediatric geneticist. A number of diagnostic systems have been developed to assess individuals for FAS (e.g., Astley, 2004; Astley & Clarren, 2000; Bertrand et al., 2004; Chudley et al., 2005, Hoyme et al., 2005). Although these various systems generally agree on the basic criteria for FAS, some significant differences exist regarding the specific thresholds for the various criteria. For example, there are different perspectives regarding the percentile for occipital frontal circumference ($\leq 10^{th}$ vs. $\leq 2.5^{th}$) that should be used to denote evidence of structural brain abnormalities. Some systems use stricter criteria for the FAS facial phenotype, whereas other systems favor relaxing the facial criteria. Similarly, there is some debate regarding whether to use the 3rd percentile or the 10th percentile as the cut-off for growth deficiency. Moreover, at this point there is no clear consensus regarding criteria to distinguish FAS from other prenatal alcohol-related conditions, such as partial FAS or alcohol-related neurodevelopmental disorder (ARND) or even consensus regarding what to call these other conditions.

   Until a clear consensus is established, clinicians will need to decide what diagnostic system to use when conducting a dysmorphology exam to assess for the physical sequelae associated with prenatal alcohol exposure. Such decisions might be informed by what system the evaluation team has the most familiarity with and access to, and the needs of their particular clinic in balancing rates of sensitivity and specificity in detecting individuals who might meet the criteria for FAS or a related condition. In general, it is best to use a system that has been well-standardized and empirically validated, and one in which the diagnosing clinician has been reliably trained. Additionally, regardless of the diagnostic system employed, it is essential to use appropriate ethnic and racial norms to avoid biases that might lead to over- or under-diagnosis. Astley (2006) compares various diagnostic guidelines currently being used.

D. The Feedback Process

1. Feedback to the family

a. *Goals of feedback to the family.* There are three primary goals of providing feedback to the family. First, the feedback team reports the results of the evaluation and recommended interventions. Such information should include specific diagnostic information (i.e., whether the individual meets criteria for FAS or another alcohol-related condition and why; whether the individual meets criteria for any co-morbid psychiatric disorders), as well as feedback about the individual's current level of functioning across multiple domains (e.g., cognitive, behavioral, emotional, interpersonal/social, educational/occupational), and factors that might optimize (e.g., social support), or alternatively, impede (e.g., inter-parental conflict) the individual's functioning. A comprehensive treatment plan should be provided to the family, including specific interventions and referrals aimed at both ameliorating the individual's and the family's difficulties and capitalizing on their strengths and resources.

   Second, the feedback team should educate the family regarding prenatal alcohol exposure and fetal alcohol spectrum disorders. Providing education to the family might help them

adjust their expectations of the individual so that they are more realistic and in line with the individual's strengths and weaknesses, and it might decrease the likelihood that the family will make negative attributions regarding the individual or their own care giving capacities. Additionally, such education is essential as it will increase the family's ability to advocate for the individual, particularly since many professionals they encounter might not be familiar with the effects of prenatal alcohol exposure or FASDs. Educating biological parents about the risks of prenatal alcohol exposure is also critical to decrease the likelihood of future children in the family being born with fetal alcohol syndrome or another related condition. As noted earlier, in families in which one child has already been born with FAS, subsequent children are at a greatly increased risk of also being born with FAS (Abel, 1988). The team should educate the family regarding strategies for navigating social service agencies and the educational system, particularly in light of a diagnosis of FAS or another alcohol-related condition. Parents might need information about regional centers or other state-funded agencies that provide services for individuals with developmental disabilities. This information should include the kinds of services provided by such agencies and eligibility criteria. Parents might need information about the Individuals with Disabilities Education Act (IDEA) and the special education process. It is also important to discuss with parents and caregivers the possible benefits and costs of sharing the child's diagnosis with the school system.

Third, the feedback team should provide emotional support to the family as they process the results of the feedback. Emotional reactions to the feedback process will vary widely both within and across families, and it is important for team members to be prepared for those responses. Family members might experience sadness, anxiety, shock, disbelief, or denial, or some combination of these emotions. In biological families, the father might express anger towards the mother; the biological mother might express profound feelings of guilt and shame, or alternatively might be defensive. In adoptive and foster families, parents and caregivers might feel angry at and misled by the adoption or social service agency if they did not receive complete or accurate information about their child's history, and they might be dealing with feelings of grief and loss as the expectations for their child must be readjusted. Olson and Clarren (1996) have commented that "the reaction of adoptive families will depend on whether or not they knew about the possibility of fetal alcohol exposure when they decided upon adoption…" and "birth parents will experience a great deal of loss related to the child's diagnosis, and might well be stigmatized for their drinking and the child's problems" (p. 3).

b. *Structure and format of feedback to the family.* A number of considerations arise when deciding how to structure feedback to a family of an individual with prenatal alcohol exposure. First, who will be giving the feedback to the family? Will one representative of the team provide the feedback, or will different disciplines provide feedback relevant to their respective areas of expertise? Regardless of the format used, it is essential that feedback be provided in a coherent, well-organized manner that will be conducive to the family's understanding of the information presented.

On a related note, it is important that the feedback be sufficiently detailed and comprehensive so that the family comes away with a meaningful understanding of the individual's diagnosis, his or her limitations and strengths, and the treatment plan.

However, there will be a limit to the amount of information the family can absorb in the course of one feedback session; thus, they should not be overwhelmed with so much information that the feedback is rendered confusing, and ultimately, not that helpful.

Although feedback can be organized in a variety of ways, the following format might be a useful guide:

First, the team should present an overview to the family of how the feedback will be presented and then ask the family if that format is agreeable to them. Beginning the feedback in this manner ensures that the family understands what will be happening, that all of the family members' concerns will be addressed, and that the family feels like a collaborative partner in the feedback process. The team should outline the methods of evaluation that were used (e.g., clinical interviews, behavioral observations, standardized testing) so the family understands exactly how conclusions were reached.

Next, a summary of the information obtaining during the evaluation should be provided. This summary might include (a) information provided by collateral resources (e.g., teachers, previous therapists); (b) observations of the individual's behavior during the evaluation process, including ways in which the behavioral observations might inform interpretation of testing results (e.g., the individual's distractibility and hyperactivity significantly impacted his or her performance during cognitive testing); and (c) results of standardized testing, including a discussion of the clinical implications of the various testing results (e.g., "His delay in receptive language means he will probably have a hard time following verbal instructions or directions or understanding what you've asked him to do"). In addition to reviewing the individual's areas of weakness, it is also important to highlight their strengths. Parents can become demoralized if all of the feedback focuses on the individual's impairments; highlighting the individual's strengths can provide parents with some sense of hope or optimism.

After reviewing the testing results, it is appropriate to provide feedback about diagnostic issues. When giving a diagnosis, the team should consider the family's existing knowledge of the diagnosis (i.e., Did they come in with some awareness that the individual might have FAS or will the diagnosis be a complete surprise to them?), and allow the family some time to process the diagnosis, as well as ask any questions about the meaning of the diagnosis (e.g., "Does this mean she's retarded? Will he be able to go to a regular school?"). Some education can be provided to the family regarding FAS, although this should be done in accordance with their response to the diagnosis. That is, a family who had some expectation that the individual might receive a diagnosis of FAS might be open to receiving some in-depth information about the condition, whereas a family who is in complete shock regarding the diagnosis might only be able to benefit from relatively basic educational information initially. It is often helpful to review the criteria for the diagnosis and to explain how that particular individual meets those criteria. This can be especially important for individuals who do not meet the full criteria for FAS, but instead qualify for a related diagnosis, such as partial FAS or ARND, as parents might need to explain the diagnosis to others. For example, a young boy was diagnosed with partial FAS because he did not exhibit the classic facial dysmorphology associated with prenatal alcohol exposure, but he had significant CNS deficits, growth

deficiency, and confirmed exposure. At an individualized education program (IEP) meeting, one of the school personnel dismissed the diagnosis, asserting that the child did not "look like" a child with FAS. The parent was able to educate the school staff about the various diagnoses along the continuum of FASDs, and helped them to understand how her child, despite not "looking like" a child with FAS, had nonetheless been significantly impacted by prenatal alcohol exposure.

The team should then provide information regarding other factors, in addition to prenatal alcohol exposure, that might be contributing to the child's presentation. In order for parents and caregivers to develop a fuller understanding of their child, the evaluation team should explain how various prenatal and postnatal factors might have affected the child's development and functioning. Individuals with prenatal alcohol exposure have often experienced other prenatal risk factors, which might include prenatal exposure to other teratogens, maternal stress during pregnancy, poor maternal nutrition during pregnancy, and poor prenatal care. Aspects of their postnatal environment or experiences, including neglect, deprivation, abuse, exposure to violence, disrupted relationships with primary caregivers, homelessness, and/or medical illnesses, might also have adversely impacted their development. Although it is likely impossible to disentangle the relative contributions of these various factors, it is important for parents to understand that the individual's presentation is likely the result of many factors, and no one single factor, including prenatal alcohol exposure, is likely to account for or explain all of the individual's difficulties.

Following diagnostic feedback, a treatment plan should be outlined for the family. Recommendations should be reviewed in order of priority, a specific rationale should be provided for each recommendation, and the family should be asked whether the recommendations seem viable and helpful. Specific referrals should be provided, and as many families of individuals with FASDs might not have private insurance, the team should ensure that the referrals being given are ones who can work with the family given their financial situation. As treatment plans for individuals with FASDs can often include multiple interventions or services, the evaluation team should help the family prioritize which interventions to seek first so that they don't feel they have to follow up on all recommendations immediately and become overwhelmed. It is important that the evaluation team consider whether there are interventions that are indicated for the parents or family as well. For example, parents who are highly stressed, demoralized, or dealing with feelings of guilt or shame might benefit from individual therapy or a support group for parents of children with FASDs; parents with current alcohol or substance abuse problems should also be given appropriate referrals.

2. **Feedback to the patient.** Depending on the chronological age and developmental capacity of the patient, it might be appropriate to provide him or her with feedback as well. Some professionals advocate providing direct feedback to all adolescent and adult patients (barring some unusual circumstance), and to some younger patients as well, if they are able to comprehend the information and their parents or caregivers are comfortable with the decision (Olson & Clarren, 1996). It has also been recommended that feedback to the patient be provided in the presence of parents or caregivers so that family members are aware of what the patient has heard, and can assist in correcting any misunderstandings (Olson

& Clarren, 1996). Although such feedback might be less comprehensive than the feedback provided to the family (particularly with younger patients), it should still aim to provide the patient with a better understanding of his or her areas of strength and weakness, how these areas of strength and weakness might impact his or her functioning in everyday life, and what interventions and resources can be made available to help him or her. Typically, adolescents and adults (and children when appropriate) are informed of their diagnosis, and such information might create mixed feelings for the patient. On the one hand, they might feel relief at finally having a name for their problems, but they might also feel angry, betrayed, and/or hurt by the knowledge that their mother's actions may have played a significant role in their difficulties. While it is recommended that the evaluation team not communicate the diagnosis in a way that ascribes negative intentions to the biological mother, it is also important to allow patients the opportunity to express and process negative feelings they might have towards their mother regarding her drinking during pregnancy and its potential impact on their life (Olson & Clarren, 1996).

3. **Feedback and consultations to other professionals.** Feedback should be provided not only to the families, but also to other professionals who work with the alcohol-affected individual and do not necessarily have expertise in FASDs. Although knowledge of FASDs is improving, there remains a need for greater education and training among health care providers (Gahagan et al., 2006; Paley et al., 2006; Payne et al., 2005), and school professionals (Caley, 2006; Finlay & Sorenson, 1995; Mack, 1995). Indeed, a growing number of resources are available online that can be useful to providers in the community (e.g., www.cdc.gov/ncbddd/fas; www.nofas.org; http://fasdcenter.samhsa.gov; http://www.thearc.org/fasproject/fasresources.htm;), but many might be unaware of how to access such resources. Providing feedback to other professionals regarding diagnostic and treatment issues for the children evaluated (with the parents' permission), as well as more general consultations regarding how to identify and work with individuals with FASDs, has been found to be helpful. Additionally, sending other professionals handouts and directing them to readings and online resources about working with individuals with FASDs have also proven to be valuable. Other professionals are typically very receptive to such feedback and consultation and very appreciative of being directed to appropriate resources.

4. **Team debriefing.** A number of issues can arise for team members when conducting assessments of individuals with prenatal exposure. Although such issues will ideally have been addressed during the course of the assessment, they might merit additional discussion at the conclusion of a case. Team members might have feelings about the individual's level of impairment and his or her prognosis, about the parents or caregivers and their role in the individual's life, including ways in which they might impede or facilitate the individual's development, and about the parents' or caregivers' response to the diagnosis and recommendations. Feelings of anger, sadness, frustration, or helplessness are not uncommon when working with alcohol-exposed individuals and their families. Such emotions might be more common among trainees who are relatively new to the field of FASDs and are still coming to terms with their feelings about mothers who use alcohol (and possibly other teratogenic substances) during pregnancy. It is also not uncommon for team members to feel frustrated with other medical or mental health professionals, or school personnel, if they feel the alcohol-exposed individual hasn't been appropriately diagnosed or provided with an

adequate level of services. It is important for such feelings to be processed in the context of the team, so that such feelings do not prevent team members from working effectively on behalf of the alcohol-affected individual and his or her family.

Suggested Learning Activities

- Lead a group discussion about the challenges, opportunities, and barriers at each point of the FAS diagnosis and services process. Discuss who is the appropriate professional(s) at each point and what is the role of the multidisciplinary team.
- Use case studies of persons with various characteristics and histories to generate discussion for considerations in referring for FAS diagnostic evaluation.
- Use case studies to illustrate how the Framework for FAS Diagnosis and Services (Figure 5.1) is put into action.
- Use role plays to provide learners opportunities to practice screening, assessment, and providing feedback to families and persons with FASDs.

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Learning Goals and Related Objectives

Goal V-A: Describe the "Framework for FAS Diagnosis and Services"

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe the elements of the "Framework for FAS Diagnosis and Services." (K)	▪ Use the "Framework for FAS Diagnosis and Services" in practice. (S)	▪ Train other health professionals to use the "Framework for FAS Diagnosis and Services." (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal V-B: Explain the diagnostic criteria for FAS

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe the facial characteristics present in a child with FAS. (K) ▪ Explain how facial characteristics of a person with FAS might differ by age and ethnicity. (K) ▪ Describe the growth abnormalities that exist in a person with FAS, adjusted for age, gender, gestational age, and race/ethnicity. (K) ▪ Describe the CNS diagnostic criteria that might be seen in a person with FAS in three categories (structural, neurological, and functional). (K) ▪ Describe the role of alcohol exposure as a criterion for FAS. (K) ▪ Describe how the salient criteria for FAS vary across the lifespan. (K)	▪ Recognize the facial features characteristic of FAS. (S) ▪ Recognize the growth abnormalities that exist in a person with FAS, adjusted for age, gender, gestational age, and race and ethnicity. (S) ▪ Recognize the CNS diagnostic criteria that might be seen in a person with FAS in three categories (structural, neurological, and functional). (S)	▪ Train other health professionals to describe the salient criteria of FAS. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal V-C: Understand appropriate criteria for referral for an FAS diagnostic evaluation

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe why front-line providers are often uncomfortable making referrals. (K) ▪ Explain when to refer for full FAS evaluation in the presence of known prenatal alcohol exposure. (K) ▪ Explain when to refer for full FAS evaluation in situations with unknown prenatal alcohol exposure. (K)	▪ Refer for full FAS evaluation in the presence of known prenatal alcohol exposure. (S) ▪ Refer for full FAS evaluation in situations with unknown prenatal alcohol exposure. (S)	▪ Educate other health professionals about the referral process. (S) ▪ Train other health professionals to use the CDC Guidelines for Referral and Diagnosis. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal V-D: Understand the assessment, evaluation, and feedback process

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Identify characteristics of fetal alcohol spectrum disorders (FASDs). (K) ▪ Describe the relationship between prenatal alcohol exposure and physical effects as well as CNS effects. (K) ▪ Explain to caregivers and families the secondary disabilities and lifelong consequences associated with alcohol exposure for individuals with FASDs. (K) ▪ Screen individuals using CDC Guidelines for Referral and Diagnosis. (S) ▪ Identify structural, growth, neurological, or functional problems that merit referral to a specialist(s) for differential diagnosis. (K) ▪ Recognize that parents have legal rights with respect to educational intervention, and know how to access that information. (S) ▪ Recognize the need to review the individual's chart for appropriate follow-up information. (A) ▪ Identify what follow-up was completed and what is still needed. (K) ▪ Recognize when an urgent referral is needed. (K) ▪ Identify concerns of patient, parent, and clinician. (S)	▪ Explain the lifelong consequences associated with alcohol exposure to persons with FASDs, to caregivers. and to the public. (K) ▪ Evaluate patients for possible FASDs using diagnostic criteria from the CDC Diagnostic Guidelines. (S) ▪ Conduct differential diagnosis. (S) ▪ Develop intervention plan and make appropriate referrals for individuals with FASDs. (S) ▪ Explain how multidisciplinary evaluations will indicate what services are needed for the individual. (A) ▪ Identify the individual's needs and know what services are available to respond to those needs. (K) ▪ Use specific screening tools, or ask specific questions to ascertain culturally appropriate services for the individual. (S) ▪ Explain the state and federal laws, as needed for appropriate follow-up services. (S) ▪ Acknowledge that the caregiver can provide essential information to determine if provision of services were successful. (K) ▪ Explain how to manage urgent follow-up for an individual. (K) ▪ Recognize prevention strategies that might maintain stable functioning of the individual and family. (K) ▪ Evaluate needs for further assessment of an individual, including co-morbidities. (K)	▪ Teach other health professionals about the lifelong consequences of prenatal alcohol exposure. (S) ▪ Train other health professionals to use diagnostic tools correctly as part of a comprehensive evaluation. (S) ▪ Train other health professionals to use differential diagnosis to determine if an individual has FAS or a related disorder. (S) ▪ Explain that multidisciplinary assessments are necessary for quality of care, and believe interpretation of results will result in appropriate referral. (A) ▪ Appreciate barriers to follow-up success, including cultural issues, socioeconomic issues, family issues, and organizational issues. (A) ▪ Acknowledge that there has to be communication between referral source and service providers for success. (A) ▪ Access appropriate follow-up services, dependent on individual needs. (K) ▪ Maintain up-to-date knowledge and information on best standards of care for disabilities, and changes in area/state/federal service programs. (S) ▪ Develop and monitor prevention programs. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

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

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

Learning Goals

(Learning objectives for each goal can be found at the end of this section.)

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 family support services and resources.

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
- F. Families and caregivers

II. Providers and approaches to treatment for FASDs
- A. Medical, mental health, and therapeutic considerations
- B. Psychopharmacological considerations
- C. Behavioral and educational interventions
- D. Alternative approaches

III. Family support services and resources
- A. Parenting strategies
- B. Disability services
- C. Legal system
- D. Resources

Also included in this section are:

- Suggested learning activities.
- References.
- Chart of all learning goals and objectives for this competency.

I. Concerns Across the Life Span

Kathleen Tavenner Mitchell, MHS, LCADC; Jacquelyn Bertrand, PhD; Tara Rupp; Susan Adubato, PhD; and Barbie Zimmerman-Bier, MD

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. Disabilities that are not addressed early not only persist, but 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, 1997).

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 go awry. In an infant or preschooler, typical, or normal, development is established by the accomplishment of particular milestones at particular ages in a standard sequence (Kessen, 1999; Behrman & Kliegman, 1998). For example, for 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 at 9 months, walk at 11 to 12 months, and run smoothly at around 14 months. This is considered developing on schedule. 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; Scheerenberger, 1983). The term intelligence quotient (IQ) derives from this concept: age of mastered material divided by chronological age (times 100) would equal 100 for someone who was learning at the same rate as his or her chronological peers.

Developmental disabilities arise 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 nonroutine 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 particular 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 (Kessen, 1999; Behrman & Kliegman, 1998; Scheerenberger, 1983). Older children who are learning new material at a significantly slower rate than their peers are considered to have an intellectual disability (formally referred to as mental retardation). 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 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 (Kessen, 1999; Spreen, Risser, & Edgell, 1995; Zigler & Hodapp, 1986). This latter path of development often results in "peaks and valleys" of strengths and weaknesses, which very much describes individuals with FASDs (Streissguth, 1997). 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 for early language, vocabulary and syntax are strengths, other social aspects of language might be impaired, such as understanding social boundaries, reading social cues, and relating to peers (O'Connor et al., 2007; Thomas, Kelly, Mattson, & Riley, 1998).

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. 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. 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 (Behrman & Kliegman, 1998; Spreen et al, 1995).

Across the life span, several protective factors have been shown to improve functioning for individuals with prenatal alcohol exposure: stable nurturing care giving, early diagnosis, absence of violence, stable home placements, and eligibility for social and educational services (i.e., special education) (Streissguth, Barr, Kogan, & Bookstein, 1996). Conversely, risk factors for poor outcomes also have been identified, including multiple care giving placements, early or continued exposure to violence, and failure to qualify for disability services.

A. Infants

Infants with FASDs often have sensory and regulatory problems (Coles, Smith, Fernhoff, & Falek, 1985). Issues such as poor sleep-wake cycles, irritability, failure to thrive, and nursing difficulties are reported frequently. Hypotonia and fine motor problems (e.g., weak grasp) are also reported (Jones, 2006). Physical therapy or generalized early intervention can be very beneficial. Additionally, infants with FASDs often have poor immune function and experience multiple bouts of otitis media and upper respiratory infections. 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

Parents generally begin to suspect delays or problems at this stage of development, regardless of the developmental disabilities. For parents of children with FASDs, common areas of concern include fine and gross motor delays, failure to comply, and loss of previously learned material (Mitchell, 2002). Disabilities that were present in infancy might also continue or increase in severity during this period, including regulatory problems, poor sleep patterns, or toileting difficulties (especially mastering this skill then regressing). Children with FASDs at this age often present as fidgety, easily distracted, and unable to focus attention. Sensory issues might emerge at this time or become more pronounced, with hypersensitivity to certain food textures, sounds, and fabrics. Physically, toddlers and preschoolers with FASDs might be short for their age and be prone to infections and colds. Conditions often suspected at this age as a result of these behaviors are attention-deficit/hyperactivity disorder (ADHD), conduct disorder, and oppositional defiant disorder. Increasingly, studies are documenting psychiatric sequelae

associated with prenatal alcohol exposure (O'Connor et al., 2002; O'Malley & Huggins, 2005; Streissguth & O'Malley, 2000).

A particular concern for children with FASDs is attachment disorders or reactive attachment disorder (RAD). This social and emotional disorder is characterized by disrupted emotional bonding between child and caregiver that results in a variety of abnormal social responses, including indiscriminate approach to strangers, poor boundaries, and lack of social understanding or empathy (Olson, Morse, & Huffine, 1998). RAD can result from neglect, abuse, and multiple caregivers within a short time or early in life. These factors are very common in substance-abusing families and even in the foster care environment. Children with RAD or any attachment issues should be referred as young as possible to a mental health or abuse professional for assessment and an individual treatment plan, which could include medication, play therapy, or even intervention from Child Protective Services (CPS) (Olson et al., 1998).

C. School-Age Children

Consistent with findings from developmental studies of typical children, neurodevelopmental functioning becomes less centralized or global and more specified during the school-age years (Kable & Coles, 2004). This differentiation of skills and abilities often leads to identification of weakness and vulnerabilities for school-age children with FASDs. However, it should be noted that deficits in neurocognitive functioning for school-age children with FASDs still occur across all areas and domains of function. In addition, school-age children might continue to manifest delays in adaptive functioning and regulatory problems. Unaddressed core deficits, weakness, and vulnerabilities during this period can lead to the development of secondary disabilities, such as disruption of school, criminal activity, and mental health problems.

Attention problems are particularly common complaints during early and middle school years. Problems reported often include difficulty sitting in class, problems with focus, poor impulse control, difficulty learning, attention disorders, and often problems with sleep. By this time, many children with FASDs have been diagnosed as having attention-deficit/hyperactivity disorder (ADHD), conduct disorders, learning disabilities, or various mental health disorders. Such diagnoses might or might not be appropriate. As learning requirements become more abstract and less concrete during the school years, executive functioning deficits become more apparent. One area where such executive function problems manifest is difficulty understanding cause-and-effect relationships and difficulty learning from mistakes. This can lead to problems with behavior (temper tantrums, outbursts) 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; Streissguth et al., 1996). In fact, weaknesses and deficits in these domains are one of the earliest and most robust findings for this population (Bertrand et al., 2004; Streissguth, 1997; Streissguth et al., 1996). 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 (Mattson & Riley, 1998). Further, deficits in visual perception, visual memory, visual-motor integration (i.e., drawing and writing), and spatial memory have been reported by many investigators (see review in 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).

Finally, during the school years, social skills problems are likely to be identified. Unlike their peers, children with FASDs often display difficulties understanding social boundaries, reading social cues, and relating to peers. Resulting behaviors can cause problems in developing friends and/or put the child at risk of being abused. Children with FASDs are at high risk for victimization and do not readily understand stranger safety.

D. Adolescents and Teens

All the cognitive, behavioral, and functioning problems associated with FASDs during the school-age years continue, and might be magnified, during adolescence. The onset of puberty, increased difficulty with social understanding, and other 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 of these. They might struggle with developing personal or social boundaries and be easily led into dangerous situations. Some students with FASDs experience behavioral issues that might draw negative attention, and as a result become 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 drivers 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, possibly as a coping mechanism, as a result of peer pressure, or due to increased genetic susceptibility.

A particularly difficult aspect for older children, adolescents, and adults with an FASD is the "hidden" nature of the disorder and its specific disabilities. This is especially true for individuals without a correct FASD diagnosis or a late diagnosis. 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 don't, or having mastered material only to forget the material and need to relearn it. Again, this aspect of FASDs puts affected individuals at high risk for mental illnesses and secondary disabilities.

E. Adults

Adults with FASDs might need support in many areas of their lives. Many adults with an FASD are very articulate and might present themselves as more capable than they really are. For instance, they might be a talented musician or artist but be unable to do simple math. Their difficulty with abstract thinking and concepts might make understanding time, money, or even crossing the street an impossible task. Like teens, adults are easily led into dangerous situations and are at high risk for victimization. Adults benefit from case management and need ongoing supports such as housing, vocational rehabilitation, transportation assistance, and employment coaching. A diagnosis of a condition under the umbrella of FASDs will not automatically qualify an individual for Social Security income or disability, although many adults with FASDs need these kinds of support systems.

F. Families and Caregivers

Parenting a child, or children, with an FASD can be challenging in the best of circumstances. Many children with FASDs enter the foster care system because of substance abusing parents,

difficult behaviors, and abuse or neglect issues. A study of children in foster care in King County Washington found 15% of children had evidence of an FASD, which is more than 10 times the rate reported in the general population (Astley, Stachowiak, Clarren, & Clausen, 2002). Birth families might need to be assessed for addiction problems and might need to be referred to addiction treatment centers. All families with an individual with an FASD need counseling and resources that will support their concerns and assist them in caring for the affected loved one. A stable home environment is crucial in preventing and addressing the behavior and learning problems that are associated with FASDs. Individuals with FASDs require structure and support in all aspects of their lives. Families and caregivers are essential in helping to create environments that will support successful outcomes for individuals with FASDs. Medical and allied health professionals should address the overall health of the family environment when treating individuals with FASDs.

Beyond a supportive clinical relationship, families caring for an individual with an FASD can benefit from specific instruction about FASDs (cause, issues pertaining to developmental differences), explanation of how typical parenting practices might not be effective for an alcohol-affected child, and specific techniques shown to be helpful (see next section).

II. Providers and Approaches to Treatment for FASDs

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Assisting families that are dealing 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 intervention. Research is currently underway to investigate successful interventions for individuals with FASDs and their families.

A. Medical, Mental Health, and Therapeutic Considerations

Children, adolescents, and adults with FASDs have all the same health and medical concerns as the general population, such as well-baby care, vaccinations, good nutrition, exercise, hygiene, and basic medical care. However, for individuals with an FASD, additional concerns specific to the disorder must be monitored and addressed either by a current doctor 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. Titles of health care providers appear in bold to demonstrate the breadth of health professionals typically involved in managing care for individuals with FASDs and their families.

The **pediatrician**'s role in identifying a possible FASD is crucial in the early intervention process. Some pediatricians feel confident to diagnose FAS based on the Institute of Medicine (IOM) recommendations (Institute of Medicine, 1996) or the CDC FAS Guidelines for Referral and Diagnosis (CDC, 2004). Others will refer the child to a **dysmorphologist** to rule out other genetic disorders that have characteristics similar to FAS (Aase, 1990). 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 patient with growth problems, possible FASDs should be considered in addition to pursuing nutritional treatments. 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). While each episode will require specific treatments, repeated bouts might be a clue to indicate prenatal alcohol exposure in children not yet diagnosed. Referral to or consultation with an **otolaryngologist, audiologist**, or **immunologist** might be warranted.

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 (Behrman & Kliegman, 1998; Levine, Carey, & Crocker, 1999).

In older children, adolescents, and adults, the **primary care provider (PCP)** serves many of the same functions as the pediatrician for younger children and infants. In addition, a PCP's role

includes case finding, case management, and providing referrals and anticipatory guidance for the families of children with FASDs. They can be instrumental in the early recognition of an FASD when addressing parental concerns of poor growth and development. Primary care providers can also assist parents with ensuring the safety of the child. They can help the family make decisions such as whether or not to place a child in a residential or therapeutic placement. Finally, referrals from PCPs are critical in integrating people with FASDs into the greater medical system (Appelbaum, 1995).

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 attention-deficit/hyperactivity disorder (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 in 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. Even 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).

Individuals with FASDs might require referral or consultation with a variety of other specialists as well. Research has shown that prenatal alcohol exposure affects fetal midface development (Astley & Clarren, 2001; Moore et al., 2002) resulting is 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 (Church ,Crossland, Homes, Overbeck, & Tilak, 1998). Thus, referral to an **ophthalmologist** might be appropriate. **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 (Romitti, 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. 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.

After referring patients with FASDs to specialists, primary care physicians should follow up with patients about the recommendations of those specialists. Specialists might not be well-educated on the neurodevelopmental issues with which clients struggle. An individual 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. Thus, as the child gets older, it will be important to have a family member or other support person familiar with the history of the child accompany the individual for his or her visits.

B. Psychopharmacological Considerations

At present, no medications have been approved specifically for the treatment of FASDs. However, several classes of medications are routinely prescribed to address common symptoms, negative behaviors, or other concerns for individuals with FASDs. Because children often see many professionals before receiving an FASD diagnosis, 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 changing behaviors, and negative side effects. Below is an overview of the major classes of medications used for children with FASDs; this list, however, should not be considered exhaustive. Before prescribing any medications for individuals with FASDs, current research and dosage information should be consulted.

1. **Stimulant medications.** Attention problems are the most common behavior disorder treated by medication in children (Baren, 1999). Children with FASDs often have attention problems such as shifting their attention or encoding material (Coles et al., 1997). These problems are in contrast to those of children with ADHD, not resulting from prenatal alcohol exposure, who have difficulty with focus and maintaining attention (Coles et al., 1997). 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 (Baren, 1999).

2. **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 (Biederman, Spencer, & Wilen, 1997). Thus, antidepressants might be prescribed for individuals with an FASD. Older antidepressants, such as MAOIs or lithium, tend not be prescribed to children. New compounds, selective serotonin reuptake inhibitors (SSRIs), 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, including 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 (Baren, 1999).

3. **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 (Feldman, Meyer, & Quenzer, 1997). 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 (Baren, 1999). Before prescribing these medications, providers should be sure parents understand these side effects so they can weigh the advantages and disadvantages for their child.

4. **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, 1999). The number of children prescribed anti-anxiety medications can be expected to rise. Anti-anxiety medications include benzodiazepine (Diazepam/ Valium), alprazolam (Xanax), clonazepam (Klonopin), lorazepam (Ativan), and buspirone (BuSpar).

5. **Drug "cocktails."** As mentioned, many children, adolescents, and adults with developmental disabilities, including those with FASDs, are prescribed multiple medications, referred to as "cocktails." Such multiple prescriptions can result from patients' 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, research into drug therapies tends not to include multiple drugs, thus their interactional effects have not been studied. As such, when new medications are considered, it is important to fully review the need and effectiveness of current medications before adding to the "cocktail" (Feldman, Meyer, & Quenzer, 1997).

C. Behavioral and Educational Interventions

Until recently, information and strategies for interventions specific to individuals with FASDs have been gleaned from interventions used 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 3 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 (Individuals with Disabilities Education Act [IDEA], 2004).

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 are not learning disabled. 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 systemic educational interventions could include special education placement. Currently, FASDs are not categorized or mentioned in the IDEA Part B legislation or regulations (IDEA, 2004). However there are several special education designations that might be appropriate for children with FASDs, including intellectual disability (previously mental retardation), specific learning disability, speech and language disorder, other health impaired, and even autism in rare cases. Section 504 of the Federal Rehabilitation Act of 1973 also provides for the education of children with special needs that do not qualify as special education students (Section 504 of the Federal Rehabilitation Act of 1973). These plans are often referred to as "504 plans". The eligibility criteria and needs of a specific child should be considered when special education referrals are made. In addition to classroom placement or classroom modifications, ancillary services might be needed, such as physical therapy, occupational therapy, speech-language pathology services, sensory integration, and recreational therapy; vocational rehabilitation might be needed for older adolescents and adults (Stratton, Howe, & Battaglia, 1996).

Some physicians and other health care professionals might be asked to include documentation to support a child's individualized education plan (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 have an IEP (U.S. Department of Education, 2000).

In addition to educational services, several adaptive interventions have been shown to be effective for children with FASDs. 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 with control children (O'Connor et al., 2007). 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 with control children with FASDs (Kable et al., 2007). Using the ALERT program (Chasnoff et al., 2008), researchers in Chicago have demonstrated improvement in behavior regulation and executive function in children with FASDs, compared with control children with FASDs. And finally, 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 et al., 2008). These research studies are important because they offer scientifically validated, efficacious interventions that can address the needs of children with FASDs.

D. Alternative Approaches

As with any disability, injury, or medical condition, many untested therapies become known and are advocated by informal networks. A physician must work with the parents or caregivers of the individual living with the particular health condition to evaluate with an open but critical mind the risks and benefits of these therapies. Some of the therapies suggested for individuals with FASDs include biofeedback; auditory training (Linden, Habib, & Radojevic, 1995); relaxation therapy, visual imagery, and meditation (especially for sleep problems and anxiety); creative art therapy, yoga, and exercise; acupuncture and acupressure; massage, Reiki, and energy healing; and vitamins, herbal supplements, and homeopathy. This last therapy is interesting in light of recent animal findings that indicate that giving choline to offspring who were exposed to alcohol prenatally might mitigate some of the resulting problems associated with FASDs. Choline plays a number of roles in brain development and is a precursor to acetylcholine, a neurotransmitter involved in learning and cognition, among other functions (Thomas, Biane, O'Bryan, O'Neill, & Dominguez, 2007).

III. Family Support Services and Resources

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A. Parenting Strategies

Keys to working successfully with children with FASDs include structure, consistency, variety, brevity, and persistence. Because these children can lack internal structure, parents and caregivers need to provide external structure for them. It is important to be consistent in response and routine so that the child feels the world is predictable. Because of serious problems with attention, it is important to be brief in explanations and directions, but also to use a variety of ways to get and keep their attention. Finally, because of possible short-term memory problems, repetition is paramount when teaching any skill (Mitchell, 2002).

Parenting a child with an FASD involves many joys and many challenges. Although each child is unique, the following list of tips can be helpful (Mitchell, 2002).

- Concentrate on the child's strengths and talents.
- Accept the child's limitations.
- Be consistent with everything (discipline, school, behaviors).
- Use concrete language and examples.
- Use stable routines that do not change daily.
- KISS: Keep it simple.
- Be specific—say exactly what you mean.
- Structure the child's world to provide a foundation for daily living.
- Use visual aides, music, and hands-on experience to assist with the learning process.
- Use positive reinforcement often (praise, incentives).
- Supervise: friends, visits, routines.
- Repeat, repeat, repeat.

Families might need additional support such as family counseling or therapy and/or parenting classes (Mitchell, 2002). In addition, parents might benefit from local support groups, in which parents of children with FASDs can discuss concerns, ask questions, and find needed emotional support.

It should also be noted that some parents, themselves, might have FASDs (diagnosed or undiagnosed) and might need to be supported as a person with a disability.

When treating birth families where drinking might still be occurring, physicians might need to ensure that families are following up on all of the recommendations made by specialists. These families might need to access support from social services to assist them in the case management process. Birth parents might need intervention and encouragement to pursue treatment for their

addiction. Child protective services might also become involved due to the addiction of the parent and the child's risk for neglect or abuse.

B. Disability Services

The search for appropriate services for individuals with FASDs is an ongoing process. Many communities lack informed providers, and it can be a challenge to secure effective services. The local department of disabilities or the local chapter of The Arc of the United States' can be a good starting point in locating appropriate services. In addition, the national Arc website can also be a good starting point (http://www.thearc.org/NetCommunity). Potential service providers should be assessed to ensure that their method of service delivery matches the methods that are effective with the particular child. The types of services an individual with an FASD might qualify for include:

- Supported employment/job coach
- Transportation
- Assisted living
- Respite care
- Social Security disability benefits
- Supplemental Security Income

The decision to apply for Social Security disability benefits involves many legal, social, medical, vocational, and psychological considerations. Applying does not guarantee that a person will receive the benefits. Additionally, to receive Social Security benefits, individuals must show that their disability has caused them to be unemployable for at least 12 continuous months. When applying for Social Security benefits, it should be considered a team effort and should include the claimant, family members, friends, health care providers, and possibly a legal representative. The financial and medical assistance available through Social Security disability benefits can be a wonderful form of assistance for individuals living with disabilities (McKee, 1997).

Federally funded Supplemental Security Income (SSI) provides supplemental income to persons who are disabled. Some children and adults with FASDs might be eligible to receive SSI. Families need to understand that their child might be eligible for this benefit before they reach the age of 18 if the parents or guardians have limited income. A child might qualify before the age of 18 if he or she has a physical or mental condition or conditions that can be medically proven and which result(s) in marked and severe functional limitations; and the condition(s) must have lasted or be expected to last at least 12 months or end in death. Health care providers can play an integral role in helping families understand the benefits available to them (Social Security Administration, 2007).

C. Legal System

It is not uncommon for adolescents and adults with FASDs to experience issues in the legal system both as victims and perpetrators of a crime (Fast, Conroy & Loock, 1999; Streissguth et al., 2004). Because of the nature of the cognitive deficits associated with FASDs, individuals are at risk for both victimization and for poor judgment or just not understanding cause and effect

as it pertains to the law. Individuals with FASDs will need a mentor or advocate to navigate the legal system. Often, physicians and other health care providers are asked to educate lawyers to properly defend a client with an FASD or to assist in developing a case for the prosecution when a person with an FASD has suffered harm. Some states offer programs for developmentally disabled offenders, and the Arc offers programs to assist disabled victims of crime.

D. Resources

The following lists of resources are by no means exhaustive, but they offer a starting place for seeking information and support.

1. Websites

- National Organization on Fetal Alcohol Syndrome: www.nofas.org
- Alcohol-Related Birth Injury (FAS/FAE) Resource Site: www.arbi.org/
- FAS Community Resource Center: www.come-over.to/FASCRC/
- Centers for Disease Control and Prevention (CDC): www.cdc.gov/ncbddd/fas
- FASD Center for Excellence: http://fasdcenter.samhsa.gov
- Fetal Alcohol Syndrome Consultation, Education and Training Services: www.fascets.org
- Fetal Alcohol Syndrome: Support, Training, Advocacy, and Resources: www.fasstar.com
- The Arc of the United States: www.thearc.org; The Arc's Family Resource Guide: http://www.thearc.org/NetCommunity/Page.aspx?pid=1400&srcid=1646

2. Newsletters

- Notes from NOFAS
  A bimonthly newsletter of the National Organization on Fetal Alcohol Syndrome. To subscribe, e-mail information@nofas.org
- Iceberg
  A quarterly newsletter published by the Fetal Alcohol Syndrome Information Service (FASIS). To subscribe, e-mail iceberg_fas@yahoo.com

3. Support Groups

- To locate an FASD support group near you, contact the National Organization on Fetal Alcohol Syndrome at www.nofas.org (National Resource Directory) or call (800) 66-NOFAS.
- FASLink
  A free Internet mail list for individuals, families, and professionals who deal with FASDs.
  www.acbr.com/fas/faslink.htm
- FAS Community Resource Center has a webpage dedicated to different types of support groups.
  www.come-over.to/FAS/fasonline.htm

- Circle of Hope
  An international mentoring program designed to connect birth mothers and other family members who have family members with FASDs.
  To subscribe, go to www.nofas.org/coh/default.aspx
- Family Empowerment Network (FEN)
- A national resource, referral, support, and research program serving families living with FASDs and the providers who work with them. There is no fee to join FEN. http://pregnancyandalcohol.org

4. **Seminars for families.** There are FASD conferences and workshops held throughout the year around the world. NOFAS maintains a current calendar of FASD and related topic conferences and workshops. www.nofas.org/events.

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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Learning Goals and Related Objectives

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

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe FASDs. (K) ▪ Identify characteristics of FASDs within all life stages. (K) ▪ Describe the importance of early identification and intervention. (K) ▪ Describe secondary disabilities associated with FASDs. (K)	▪ Identify characteristics of FASDs throughout the lifespan. (S) ▪ Identify secondary disabilities associated with FASDs. (S)	▪ Describe the importance of case management to other health professionals. (A, S) ▪ Explain FASDs throughout the lifespan to other health professionals. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal VI-B: Explain various treatment approaches

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe the types of interventions and referrals that an individual with an FASD might require. (K) ▪ Define therapeutic and mental health interventions. (K)	▪ Describe behavioral and educational interventions that have been shown to be effective for individuals with FASDs. (S) ▪ Describe alternative approaches that can be used for individuals with FASDs. (S) ▪ Explain the current role of medications in the treatment of FASDs. (K)	▪ Explain to other health professionals about various treatment interventions that might be helpful for an individual living with an FASD. (S) ▪ Explain to other health professionals about the role of medications in the treatment of FASDs. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal VI-C: Explain family support services and resources

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe parenting strategies that can be helpful in working with children with FASDs. (K) ▪ Describe disability services that might be available to individuals with FASDs. (K) ▪ Explain why individuals with FASDs often experience issues with the legal system. (K)	▪ Identify family support services and resources for individuals and families living with FASDs. (S)	▪ Explain to other health professionals the importance of family support services for individuals and families living with FASDs. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Competency VII: Ethical, Legal, and Policy Issues

The health care student or provider will be able to recognize ethical, legal, and policy issues related to FASDs.

Learning Goals

(Learning objectives for each goal can be found at the end of this section.)

VII-A Identify ethical issues related to FASDs.
VII-B Identify legal and policy issues related to FASDs.

Content Outline for Competency VII

I. **Ethical issues**
   A. Introduction
   B. Confidentiality

II. **Legal and policy issues**
   A. Fetal rights and the maternal-fetal relationship
   B. Limitations of coercive and punitive approaches
   C. A public health approach

Also included in this section are:

- Suggested learning activities.
- References.
- Chart of all learning goals and objectives for this competency.

I. Ethical Issues

Carolyn Szetela, PhD; Danny Wedding, PhD, MPH; Robert Levine, MD; and Margaret Stuber, MD

A. Introduction

All health care delivery involves ethical dimensions. Health care related to FASDs is laden with ethical issues such as weighing the rights of a pregnant woman and protecting the health of the fetus. Health practitioners are key players in advocating and delivering the best care to meet these needs. Those who carefully consider the ethical aspects of their work honor their patients and their larger communities, as well as maintaining their own integrity.

Four basic principles are commonly used to describe ethical challenges in health care settings (Beauchamp & Childress, 1983). These are autonomy, beneficence, nonmaleficence, and justice. As these principles are often in conflict with one another, none can be regarded as absolute. Health care providers might have to prioritize the principles in response to the unique situation in question.

Respect for autonomy asks health care providers to consider a person'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 Nathan 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* about his or her choices, 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 can occur with FASDs are lacking or limited in the reasoning skills necessary to exercise full autonomy. Persons with alcohol dependence or addiction might also have limited autonomy because of impaired reasoning and/or compulsion.

Pregnant women, or adults caring for someone with an FASD, are ordinarily free to make autonomous personal health care decisions, as well as to make choices regarding care for the fetus or a child with an FASD. The mother, parent, or guardian is expected to be an advocate for the fetus or child's interests. At times the health care provider might question the reasonableness of a choice made on behalf of the 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 care provider might consider available and legally permissible ways to limit the adult's decision-making authority in order to protect the fetus or child.

The principles of beneficence and nonmaleficence often go hand in hand. Beneficence asks health care providers to seek the benefit of their patients. Beneficence is an integral goal in the "helping professions." Nonmaleficence emphasizes the responsibility to avoid causing harm and to minimize undue harm to others. Together, these principles represent the weighing of benefits and risks of all reasonably considered health options. These principles apply when health care providers act to promote maternal and fetal health and prevent alcohol-related harms to women and fetuses, and when they provide competent, compassionate care for persons born with FASDs.

However, at times these principles might be in conflict when what would be of benefit to the fetus (such as restriction of the mother's access to alcohol by limiting her freedoms) might be harmful to the mother.

The principle of justice asks health care providers to consider fair distribution of social benefits and burdens (distributive justice), and to promote and follow laws and practices in ways that are fair for all people (procedural justice). Justice requires fairness to people who are affected by FASDs and to women with known alcohol use and abuse. Justice can be reflected in non-prejudicial attitudes and treatment of persons with FASDs and women who engage in at-risk or harmful drinking, and in promotion of access to the resources they need.

An additional ethical principle, "respect for persons," encompasses aspects of all four of the principles just described. Respect for persons, as applied in a health context, asks care providers to 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. This principle asks health providers to show respect for people with FASDs and women with known alcohol use and abuse, and to address their health care needs and interests.

Good ethical decision making always includes consideration of relevant city, state, and federal laws. In some cases, however, ethical and legal strictures might conflict. For example, laws denying women the right to vote in the United States, until ratification of the 19th Amendment in 1920, would now be seen as violations of the ethical principles of autonomy, beneficence, nonmaleficence, justice, and respect for persons. When existing or proposed laws conflict with fundamental ethical values, they should be subject to review and revision (American Medical Association [AMA], Council on Ethical and Judicial Affairs, 1994).

B. Confidentiality

Confidentiality is an essential aspect of the health provider–patient relationship. Health providers learn 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 offering information.

The principle of confidentiality is not absolute. Among its possible exceptions are cases where health providers learn information that might, with reasonable probability, indicate serious bodily harm to the patient or others (AMA, 2006a). This includes learning of alcohol exposure by a pregnant patient who risks serious harm to herself and might also include risks to her fetus.

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 patient confidences, they should avoid giving a false impression that confidences might always be protected (AMA, 2007). Accordingly, care providers should inform patients about general limitations upon confidentiality in their setting, such as at the first health visit with the patient. When confidentiality must be breached, health providers should notify the patient of their need to disclose, unless impractical or inadvisable (AMA, 2006b). Care providers must stay informed of local, state, and federal laws impacting confidentiality.

II. Legal and Policy Issues

Carolyn Szetela, PhD; Danny Wedding, PhD, MPH; Robert Levine, MD and Margaret Stuber, MD

A. Fetal Rights and the Maternal-Fetal Relationship

Fetal rights can be considered from ethical and legal perspectives. We can ask distinctly, "What status does our ethical reasoning attribute to the fetus?", and "What status do legal precepts and practices attribute to the fetus?" Both regards must ultimately address the rights of the fetus in relation to the rights of the woman who carries the fetus.

The ethical status of fetuses 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). Just what these characteristics are is 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, people agree that the well-being of each person starts during fetal development, and that we should care for both fetuses and the mothers in whom they grow.

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. The legal status of fetuses is generally subordinate to that of pregnant women. A fetus' legal status might also increase over time with its 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 satisfactory framework for conceptualizing fetal and maternal status for cases where maternal interests or behaviors might put her fetus at risk. When maternal and fetal interests are distinct, any resolution might compromise the ethical interests of the woman, the fetus, or both.

B. Limitations of Coercive and Punitive Approaches

Preventing the harms of prenatal alcohol use carries great ethical urgency, as prevention serves to benefit fetuses throughout their lives and avoid possible great 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 enacted a statute allowing pregnant women whose habitual drinking exposes a fetus to substantial risks of physical harm to be taken into custody and undergo involuntary inpatient alcohol treatment (Linder, 2005). Other states have proposed or enacted bills that respond to women who expose a fetus to the harms of alcohol in pregnancy by means 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], 2006).

Many previous 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). Currently, South Carolina remains the first and only state whose law recognizes the viable fetus as a person and accordingly permits criminal prosecution of women for endangerment of a fetus (Linder, 2005).

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). This decision sets limits on how health care providers at public hospitals can intervene to prevent fetal alcohol exposure.

Evolving opinion on ethical practices, policies, and laws regarding women who might risk alcohol- or drug-related harm to their fetuses is expressed by the American College of Obstetrics and Gynecology Committee on Ethics in their Opinion, *Maternal Decision Making, Ethics, and the Law* (American College of Obstetricians and Gynecologists [ACOG], 2005). The committee offers six objections to coercive and punitive responses to these women (See Table 7.1). Among them are considerations of women's autonomy regarding the primacy of their decisions

about their individual situations and health; considerations of outcomes such as the adverse consequences of coercive or punitive approaches upon individual women, and upon public health by discouraging women from seeking prenatal and health care (Poland, Dombrowski, Ager, & Sokol, 1993); and considerations of procedural justice regarding the strikingly disproportionate applications of coercive and punitive practices upon disadvantaged and vulnerable groups of women.

An ethical and effective response to the risks of FASDs must also account for contributing factors in maternal drinking. While health 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 in pregnancy 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). 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 do not produce a lasting reduction in their risk exposure (ACOG, 2005).

Table 7.1. 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. (2005). ACOG Committee Opinion No. 321: Maternal decision making, ethics, and the law. Obstetrics and Gynecology, 106, 1127–1137.

A reasonable legal or policy response to drinking during pregnancy should also stand in balance 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 using tobacco, becoming pregnant during very early or late stages in one's childbearing years or with health conditions that pose fetal risks, and using reproductive technologies that increase the likelihood of multiple births. Also 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. However, recognition that these behaviors have not fuelled commensurate efforts to restrict and punish women or men as has occurred with pregnant women who use alcohol and drugs serves as a caution to ensure that strategies to prevent FASDs are both effective and fair (Eckenwiler, 2004).

Punitive laws used to prevent women from exposing fetuses to drugs present a number of serious ethical concerns. 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 does not optimize

benefit (beneficence) and the avoidance of undue harm (nonmaleficence), and it might contribute to mistrust of health care providers by pregnant women who are in need of trusted care. ACOG and a host of health advocacy groups have issued strong concerns or recommendations against punitive approaches, 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.

C. A Public Health Approach

As an alternative to punitive interventions, education and drug and alcohol abuse treatment are proactive measures to prevent the harms of prenatal alcohol exposure. Health care providers can send the message to women of childbearing age that "when you drink, your baby drinks," and encourage effective use of contraceptives as well as preconception abstinence from alcohol. As Floyd, Ferguson, and Hungerford (1999) stated, "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" (p. 101). Many women do not recognize the dangers of alcohol to a fetus, and social and cultural norms often tolerate or even encourage drinking in 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 in pregnancy, and a lack of time during health visits (Gahagan et al., 2006; Nevin, Parshuran, Nulman, Koren, & Einarson, 2002). Training in time-effective ways to talk with patients about alcohol in pregnancy will help health care professionals and the public become better informed in how to prevent FASDs. When health providers include preventive interventions in their routine practices, they might gain satisfaction in preventing and minimizing health problems before they arise.

For women with alcohol dependence and abuse, prevention messages alone fall short. Health care providers must screen women for alcohol use, and be able to supply referral options for women needing specialized treatment (ACOG, 2004). Unfortunately, there are often few treatment options available for pregnant women and women with dependent family members. According to ACOG (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." (Page 1134)

Many states have proposed or enacted public health interventions for FASDs. Such interventions include allocations of funds for prevention, diagnosis and registries, alcohol and drug recovery awareness events, increased access to addiction treatment, signage requirements, and community grants (SAMHSA, 2006).

Even if they were 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. A public health approach incorporating prevention and treatment could have a far greater impact, by preventing rather than punishing harmful behaviors. Studies show that pregnant women who use alcohol and drugs want to protect their fetus 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.

Summary

Health care providers seek to provide ethical care for the women, fetuses and children they serve. When drinking during pregnancy poses risk to a fetus, providers can express their respect for both woman and 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 in facilitating help, both to benefit the woman and her child or children.

The personal toll of living with an FASD, as well as the toll upon the affected individual's 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

- Use *Law and Order* video for discussion. [Harbinson, P. (Writer), & Platt, D. (Director). (2003). Choice [Television series episode]. In D. Wolf (Producer), *Law & Order: Special Victims Unit*. Los Angeles: NBC Universal Television Studio.]
- Use case studies to generate discussion.
- Use the "Mistakes I Have Made…" (Boulding, 2001) article for discussion.

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Learning Goals and Related Objectives

Goal VII-A: Identify ethical issues related to FASDs

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe basic ethical principles for health care. (K) ▪ Identify ethical principles in relation to FASDs. (K, A) ▪ Recognize patient confidentiality in relation to FASDs. (K, A)	▪ Discuss the importance of ethics in working with persons with FASDs, their caregivers, policy makers, and other health professionals. (A) ▪ Evaluate and discuss ethical issues with patients, caregivers, policy makers, and health professionals. (A, S) ▪ Discuss confidentiality issues with patients and their families. (S)	▪ Describe ethical issues related to FASDs to other health professionals. (S) ▪ Describe confidentiality issues related to FASDs to other health professionals. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal VII-B: Identify legal and policy issues related to FASDs

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Discuss fetal rights and the maternal-fetal relationship. (K,A) ▪ Discuss limitations of coercive and punitive approaches toward alcohol and drug use in pregnancy. (K, A) ▪ Identify elements of a public health approach to FASDs. (K, A)	▪ Evaluate and discuss key legal and policy issues with patients, caregivers, policy makers, and health professionals. (A, S)	▪ Educate colleagues and staff about key legal and policy issues related to FASDs. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

APPENDIX

- Terms Used in This Guide
- Strategies and Resources for Teaching and Evaluation
- Resources for Cultural Competency
- Growth Charts
- FASD Regional Training Centers Contact Information
- 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
- Learning objectives
- Skill levels

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.

Learning objectives—specific descriptions of what a learner will be able to do after instruction. They are the specific steps that the learner must achieve to reach the learning goals and, ultimately, the competencies. Objectives should be stated from the viewpoint of the learner (e.g., the learner will be able to…) rather than from the viewpoint of the instructor or program (e.g., provide resources). Objectives should be SMART (**s**pecific, **m**easurable, **a**chievable, **r**elated to the goal, and **t**ime-oriented). Because there are different types of learning, objectives can be classified as knowledge-based, attitude-based, or skill-based. Specific verbs that match the type of learning classification can be used to determine the type of activity that the learner must demonstrate to indicate the achievement of the objective.

Skill levels—designations of how skills and knowledge gained from instruction will be used (i.e., 1–knowledge, 2–practice, and 3–teaching). The competencies and goals are the same for all learners, but learning objectives are tailored to the skill set needed by learners. An instructor can select objectives around which to organize a course, seminar, or other learning experience based on their learners' needs.

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.

Strategies and Resources for Teaching and Evaluation

Martha E. Alexander, MA, MPH, CCC-SLP

This section provides a brief overview of adult education principles, teaching methods, teaching tips, and suggestions for evaluation.

Content Outline

I. **How do adults learn?**
   A. Adults prefer self-directed learning
   B. Experience facilitates learning
   C. Training should be goal-oriented
   D. Adults seek training for problem solving
   E. Feedback reinforces learning
   F. Overlearning aids retention
   G. Proper sequence of information aids learning

II. **How does one prepare for training or teaching?**
   A. Content—What do I teach?
   B. Teaching techniques—How do I teach?
   C. Evaluation—How do I know that students are learning what is being taught?

III. **How can trainers communicate effectively with learners?**
   A. Speak effectively
   B. Watch participants' body language and gestures
   C. Ask and answer questions
   D. Listen actively to participants
   E. Offer feedback
   F. Use effective handouts to promote learning
   G. Use visual aids to enhance retention

IV. **What types of techniques can be used in training?**
   A. Discussion
   B. Case study
   C. Demonstration
   D. Role playing
   E. Panel discussion
   F. Brainstorming
   G. Practice exercises
   H. Debates

V. **Evaluation**
   A. Learner reaction
   B. Learner knowledge
   C. Change in learner behavior

I. How Do Adults Learn?

Research in disciplines such as training, education, and education psychology indicates that adults learn in specific ways. Adults want their learning to be problem-oriented, personalized, and accepting of their need for self-direction and personal responsibility. Many trainings are teacher-centered, but research indicates that adults (and children, too) benefit from learning experiences that are learner-centered. These principles are applicable to classroom or distance-based learning.

The following principles of adult learning can help promote a more learner-focused environment.

A. Adults prefer self-directed learning
Typically, adults have moved from being dependent on a teacher to direct their learning to being self-directed in their learning.

To facilitate self-directed learning:

- Actively involve participants in the learning process. If possible, allow participants to select projects that reflect their interests.
- Clarify participants' expectations before beginning work on the content.
- Serve as a facilitator and guide participants to their own knowledge rather than supplying them with facts. Present yourself as someone who is available as a resource rather than someone with all the answers.
- Use case studies, role plays, demonstrations, and group discussions rather than spending the bulk of the training on lectures (see section IV for more information on these techniques).
- Encourage participants to take responsibility for presentations and group leadership.
- Include time for self-directed training by having groups generate problems for application.
- Treat adults as adults.

B. Experience facilitates learning
Adults bring a great deal of life experience to learning situations, including previous education, work and volunteer activities, family responsibilities, and leisure activities. This experience becomes a valuable resource for learning.

To take advantage of participants' experience:

- Get to know the participants and a little about their background. During training, ask participants to share something related to their background.
- Relate theories and concepts to the participants' experiences.
- Encourage participants to talk with one another and learn from others' experiences.
- Help participants to continuously relate learning experiences to job situations.

C. Training should be goal-oriented

Adult learners seek out training to gain knowledge or skills specific to tasks in their life roles, such as work responsibilities. Therefore, learning becomes more goal-oriented.

To apply this principle:

- Early in the training, find out what participants would like to achieve from the training. This could be done in class, in informal discussions during breaks, or through a brief questionnaire completed at the beginning of class.
- Explain the goals and objectives of training and how they will relate to participants' personal or professional goals.
- Use relevant, real-life examples to illustrate key points.

D. Adults seek training for problem solving

Typically, adults learners participate in training not for the sake of knowledge alone, but to apply that knowledge to solve a present or potential problem.

Training for adult learners should:

- Use examples and collaborative activities to teach problem-solving skills rather than just providing solutions to the learners.
- Encourage participants to arrive at the answer themselves. Avoid giving immediate answers.
- Reinforce participants' attempts to solve problems on their own.
- Encourage participants to use information from a variety of disciplines to solve a problem rather than using knowledge from only one discipline.
- Use stories from your experiences and relate them to the participants' situations.

E. Feedback reinforces learning

Learning that is positively reinforced is more likely to be remembered and applied. Adults want to see the results of their efforts. Feedback lets participants know how they are progressing.

- Provide positive feedback as soon as possible to increase the value of the response.
- Give constructive feedback about efforts.
- Nod when you agree.
- Compliment correct answers. If an answer is partially correct, acknowledge the accurate parts before correcting the incorrect parts. If incorrect, correct the answer but thank the learner for their effort.
- Comment on hard work and contributions to discussions and group activities.
- Organize opportunities for peers to provide feedback and reinforcement to each other. This could be done in group projects, small group exercises, or discussions.

F. Overlearning aids retention

Overlearning decreases the rate of forgetting information.

- If there was a prior session, review it before introducing new information.
- At the beginning of training, provide an overview of what will be discussed in the training.
- State and restate key ideas throughout the training.
- At the end of class, review the training and provide two or three key points that summarize the most critical information.
- Provide a variety of opportunities for repeated practice of new skills. For example, pair lectures with discussions, exercises, and role plays.

G. Proper sequence of information aids learning

Learners tend to remember what they heard first and last. Information in the middle of a training session has to compete with the information that comes before and after it, so it is remembered less well.

When putting together a training session:

- Discuss critical information first and last.
- Preview the information to come at the beginning of training, and summarize the information at the end of training.
- Emphasize the middle part of training sessions by using an activity or visual aids.
- Summarize throughout the session.
- At the end of a session, give the participants two or three key points.

II. How Does One Prepare for Training or Teaching?

Learners appreciate a well-organized instructor. An organized lesson shows respect for learners and helps them to follow and understand the content of the lesson. When preparing a training session, answer three questions:

- What do I teach?
- How do I teach it?
- How do I know that students are learning what is being taught?

A. Content—What do I teach?

All instructors face the challenge of deciding what specific content to teach. The hardest decision is usually deciding what topics will be omitted so that the session is manageable. Following are steps to consider when planning your session:

- Review the training needs assessment. This document explains how specific sessions were selected. It is also a good way to learn more about the participants, if you are not familiar with their training needs. The more a trainer knows about the needs of the trainees, the more closely the session can be tailored to meet their needs.

- Review the goals and objectives that have been established for your session. The goals are the broad, long-range skills learners should achieve. The objectives are the more specific steps that the learners must be able to do to achieve the goals. These learning objectives answer the question, "What will the trainee be able to do (or do differently) after training that he or she could not do before the training?" The objectives specify what the instructor will teach. Objectives may also be referred to as learning outcomes.
- Based on the learning objectives, develop a list of topics for the lesson.
- Decide what is essential information and what is optional based on the time available for your lesson.
- Emphasize the critical skills or ideas that trainees will need to achieve the objectives.
- Arrange the course content logically. Content can be arranged chronologically, by category, from concrete to abstract or vice versa, from theory to application or vice versa, by increasing level of skill or complexity, or from a broad to a detailed perspective or vice versa.
- Write out a lesson plan detailing specific information about the lesson (see Tables A.1. and A.2.). This tool can assist in planning and conducting the lesson/training session and be reused for future trainings, with modifications as needed for future participants.

B. Training techniques—How do I teach?

Developing appropriate content is not enough. It must be presented in a way that is appropriate for the purpose of the training and the needs of participants.

- Select appropriate techniques based on the objectives. Ask, "What will the students do to achieve that learning objective?" Active techniques are better than passive. For instance, one learns to solve problems by solving problems; one learns to think critically by thinking critically. Refer back to what you know about participants. How do they learn best? What teaching techniques have been used before? What techniques worked well? What techniques did not work? Why?
- Design activities, exercises, handouts, and other materials. Again, consider the trainees. How do they learn best? How can you customize materials and activities to meet their needs?
- Decide if you will use any audiovisual equipment and how you will incorporate it.
- Select appropriate references that you can suggest to trainees for additional learning.

C. Evaluation—How do I know that students are learning what is being taught?

After the training, it's important to know whether, or how much, participants learned. Feedback gained from the course/session evaluation will help improve future trainings. In a multi-session training, feedback after the first session can alert the trainer to any changes that should be made to improve learning on subsequent days.

- Prepare a list of questions that you can ask the trainees.
- A pre-test/post-test can be used, but consider what other types of evaluations you can do to ensure that the trainees understand the lesson (see section V for more information about evaluation techniques).

Table A.1. Sample Lesson Plan Format

Instructor:	Date:
Course:	Lesson Title:
Learning Goal(s):	
Learning Objective(s): By the end of the lesson, the learner will be able to:	
Key Points of Lesson:	
Materials/Media Needed:	
Lesson Description:	
Lesson Content: • Introduction (introduce the topic in an interesting way, tell the trainees what they will learn in the lesson and what they will do) • Lesson Outline (what you will talk about, teaching techniques you will use, how you will involve the trainees, discussion questions, etc.) • Conclusion (summarize what was done in the lesson, suggest readings or activities for additional learning, reinforce key points of the lesson, suggest how trainees can use information at their job)	
Assessment/Evaluation (how will you determine if the information has been learned?):	
References:	

Table A.2. Lesson Plan Checklist

- The lesson plan states at least one clear, understandable goal.
- The lesson plan clearly states one or more reasonable, achievable, action-oriented objectives.
- Lesson plan objectives are related to the goal and purpose of the lesson.
- The introduction provides an overview of the lesson plan objectives and what will happen during the lesson; the introduction motivates trainees about the topic.
- Training activities are based on the learning objectives and relevant to the trainees' needs.
- The lesson plan uses a variety of teaching techniques.
- Content is appropriate for the trainees' needs and their current skills.
- The amount of instruction is appropriate for the amount of time available.
- Trainees are given time to practice and apply what they learn during the lesson.
- Media and materials are practical, available, and appropriate for participants' needs.
- The summary reinforces the lesson and provides suggestions for how trainees can apply what they learned in the jobs.
- Time is allotted for discussion and questions and answers.
- An evaluation of trainees is planned.

III. How Can Trainers Communicate Effectively With Learners?

Good teaching involves effective communication. Following are suggestions to enhance communication in the training session.

A. **Speak effectively**
What we say involves more than just the words we use. Words account for only 7% of what is communicated. Gestures and body language account for 38%, and tone of voice accounts for 55%.

Effective speakers:

- Use direct eye contact.
- Vary voice pitch to create more interesting speech.
- Use appropriate gestures to emphasize points.
- Look around the room slowly, and avoid looking up and down.
- Breathe regularly to avoid running out of breath.
- Stand with a relaxed posture.

B. **Watch participants' body language and gestures**
Participants' body language can provide an indication of how well communication is occurring. Gestures to look for may include:

- Frowns (confusion or disagreement).
- Hand over mouth (sign of a stifled yawn, boredom).

- Lack of eye contact.
- Sitting on the edge of a chair (could be a sign of interest or eagerness to leave).
- Arms folded across chest (could mean resistance or that people are cold).

C. Ask and answer questions

The give-and-take of questions is an important part of communication. Good questions are stimulating and thought provoking. Ask questions that call on participants' experience, views, or opinions. Allow time for questions from participants; these can clarify or expand on the lesson's key points.

Ask participants questions:

- Plan questions before the training session.
- Try different kinds of questions:

  The direct question—Make eye contact with a particular participant and call on him or her by name to answer the question. Use this method with caution, as it can be very intimidating to some.

  The group question—Ask the question to the group and then ask someone from the group to answer.

  The "all together" question—This question is directed to the whole group and solicits a group response. For example, "The reason we need to use this type of surveillance is_____?"

- Create an environment where participants feel safe in answering questions. Participants must know that whatever their answer, the presenter will not ridicule them.

Respond to participants' questions:

- Encourage participants to write down their questions as they occur throughout the training session.
- Invite questions with open-ended questions, such as, "What questions do you have?" (not close-ended questions, such as, "Do you have any questions?")
- Listen to the entire question and avoid interrupting the questioner.
- Repeat and/or rephrase the question so that the whole class can hear it and to ensure that you heard the question correctly.
- When a question is asked, make direct eye contact with the questioner. When answering the question, break eye contact and direct your attention to the entire audience.
- Redirect the question back to the group. For example, "Does anyone have a suggestion for solving this problem?" This method allows you time to gather your thoughts and think about your answer. It also stimulates thinking skills in trainees.

- Direct the question back to the questioner. For example, "Good question. What do you think?"
- Create an environment in which participants feel safe asking questions. They need to know there's no such thing as a "dumb" question.

D. Listen actively to participants

Listening actively involves more than hearing words and then verbally responding. It includes the acceptance and affirmation of the speaker. If a person does not receive this acceptance, he or she will most likely not feel welcomed or want to be a member of the group; these feelings can inhibit learning.

To listen actively:

- Encourage trainees with simple responses such as "mmmm" or "uh-huh"; the trainee will feel that he or she is being listened to and should continue.
- Restate what you are hearing and what you understood with statements such as "In other words, what you suggest is…."
- Reflect what you think the trainee might be feeling with comments such as "It sounds like you feel very strongly about this."
- Summarize discussions; this is a good way to bring a conversation to an end, but make sure that the lines of communication remain open.

E. Offer feedback

Another important part of communication is feedback. Feedback helps people know how they are doing. It should always concentrate on improving style, not destroying confidence.

- Give feedback at the earliest opportunity after the given behavior.
- Begin with positive comments first.
- Be very specific.
- Give constructive feedback in a nonjudgmental way.
- Direct feedback toward behavior that the receiver can do something about.
- Provide alternatives to actions or responses as part of feedback.
- Create an environment so that feedback is a positive experience.

F. Use effective handouts to promote learning

Handouts are a written form of communication. They may be used by trainers to promote interaction and communication between the training participant and the learning material, between the trainer and the participant, or among students.

Effective handouts have the following characteristics:

- A focused goal. The handout should fill a need for the learner.

- Inclusion of only essential information, presented in a logical manner.
- Clear, descriptive headings.
- Easy-to-read type face and font size.
- Adequate white space so that trainees can add their own notes. A good guideline is to fill no more than two thirds of the page with words or graphics.
- Use of formatting to draw attention to key points (bold, italics). Stick to a couple of formatting tools or the handout will look cluttered
- Graphic elements (diagrams, charts, etc.) that illustrate key points.
- An activity or exercise that leads students to interact with the material and/or each other. Such activities enhance learning.

G. Use visual aids to enhance retention

It has been estimated that what audiences see is retained twice as long as what they hear. Visual aids are important training tools that supplement or enhance a training session. When used effectively, they aid communication and provide variety in a lesson. Visual aids include flipcharts, chalkboards/whiteboards, overhead transparencies, slides, PowerPoint presentations, films, video podcasts, job aids, and videotapes.

The following questions will help in selecting visual aids:

- Does the content require a visual aid?
- Will the visual aid focus on the key points?
- Which visual aid is appropriate?
- Will I be able to use the visual aid appropriately?

Table A.3. provides characteristics of effective visuals aids. Table A.4. compares various types of visual aids.

Table A.3. Characteristics of Effective Visual Aids

Visual aids should be:	Tips:
Visible	All trainees should be able to see the information. Make sure that the font size is large enough for the entire group to read.
Simple	A visual aid should simplify the material. Make sure key words and concepts are highlighted and uncluttered.
Accurate	Use current information. Update any visual aids you have used before to reflect most recent information.
Interesting	Design promotes retention. Use colors and illustrations to attract attention, but use them in moderation. Too many colors, illustrations, and special effects are very distracting.
Practical	The visual aid should add to the presentation. It should fit into the flow of the presentation, not distract from it.

Table A.4. Comparison of Visual Aids

Type	Advantages	Disadvantages	Tips
Flipchart	Inexpensive, flexible, portable, can involve trainees	Legible handwriting required.	Can be made up in advance; leave blank page in between pages (markers may bleed through); use wide-tipped markers; make lettering tall enough for all to see.
Whiteboard or chalkboard	Easy to alter	Special markers needed for whiteboard; chalkboard may be dusty; legible handwriting required.	Before the lesson, make sure you have eraser, chalk or whiteboard markers, cleaner; clean boards to remove old lettering; avoid light shining directly on board to prevent glare.
Overhead projector and transparencies	Direct eye contact with trainees, room lights do not have to be dim, more easily seen by large groups than flipcharts, easy and economical to produce, equipment widely available	Projector arm can interfere with some trainees' vision of screen; bright light on white screen can be tiring.	Avoid walking between screen and projector; place projector to side of room so all trainees have full view of screen; turn projector light off when a transparency is not on the screen.
Slides	High quality, equipment widely available	Room needs to be darkened; can put trainees to sleep; requires time to produce and process.	Test equipment before session; run all slides through once to make sure they are in order; know how to fix a slide that sticks; turn projector off at end of session; avoid showing slides right after lunch.
Computer presentations (such as PowerPoint)	Polished presentations, can save and adapt for future trainings, can modify at the last minute	Expense of computer and projection equipment; requires technical expertise; could face compatibility problems between software programs and computers.	Check before training about compatibility in operating systems and programs; have a back-up strategy if equipment fails; avoid too many details on screen; stay learner-focused (don't use every fancy feature on the computer).
Video	Can be dynamic, easy to transport	Can be expensive, need to understand use of controls.	Always preview video before use; if using only a portion of video forward it to segment before class; use an appropriate volume for all to hear; place lighting at a level that allows trainees to take notes; pause throughout to encourage discussion.

IV. What Techniques Can Be Used in Training?

Adults learn in a variety of ways. To address the needs of all participants, it is necessary to use a variety to teaching techniques. This section describes some of the more common training techniques. No one technique is perfect for any situation. The decision of what technique to use should be based on:

- The needs of the trainees.
- The learning objectives.
- The skills of the facilitator.

A. Discussion

A discussion is a group activity in which the trainer and trainees talk about specific problems or topics. It is an active learning process. Discussions might take place with the whole class, or the instructor might place trainees in small groups to discuss a problem and then report back to the larger group.

1. Advantages of discussions

   - Allows everyone to participate.
   - Provides for trainer and trainee involvement and interaction.
   - Allows thinking aloud to revise errors in judgment.
   - Involves creative and critical thinking.
   - Helps to develop insight into problems and an awareness of various viewpoints.
   - Develops abilities to work as a team.

2. Disadvantages of discussions

   - Can be time consuming.
   - Is not as effective with large groups as small groups because not everyone will have a chance to participate.
   - Might allow a few trainees to talk most of the time.
   - Might cause participants to lose focus or stray off topic.

3. Tips for leading effective discussions

   - Help the group set rules before discussion.
   - Plan how you will conduct the discussion.
   - Pose a question (can be controversial) and give students a few minutes to jot down an answer.
   - Make a list of key points before the session.

- Have students divide into small groups to discuss a question and then report to the larger group.
- Use nonverbal cues to maintain the flow. Listen to participants' comments and rephrase, if needed.
- Keep the discussion focused. Prevent the discussion from straying off topic or deteriorating into a heated argument.
- Vary the emotional tone of the discussion.
- Be alert for signs that a discussion is breaking down.
- Model communication behaviors you want trainees to follow.
- Bring closure to the discussion by summarizing key points.

4. Tips for encouraging participation during discussions
   - Learn trainees' names so you can address them by name. Encourage trainees to know each other's names, if they don't already.
   - Allow time to warm up before you launch into discussion.
   - Limit your own comments.
   - Arrange room to promote discussions (make sure everyone can see each other).
   - Periodically, divide trainees into small groups so more people can participate.
   - Give quiet students special encouragement. If students tend to monopolize the discussion, talk with them during a break. Let them know that you appreciate their comments but that you would like to encourage other students to talk, too.
   - Tactfully correct wrong answers.

B. Case study

In a case study, learners are given problems, verbally or in writing, that are similar to those that might occur on the job and are asked to analyze the problem.

1. Advantages of case studies
   - Develops problem-solving skills.
   - Gives a real-life example, similar to a job-related situation.
   - Involves participants actively.
   - Is systematic.
   - Can stimulate discussion.

2. Disadvantage of case studies
   - Can be time consuming.

3. Tips for facilitating case studies

- Read the case in advance. Note learning objectives and key teaching points. Develop a list of prompts in case students have difficulty answering the questions on the case study.
- At the training session, introduce the case briefly. If learners are not familiar with case studies, explain the purpose of case studies as a teaching tool.
- Explain the process of the case study. Decide beforehand whether the learners will read the case study aloud or silently. Although learners generally prefer to read silently, reading aloud ensures that all learners stay together and helps to eliminate people reading ahead or falling behind.
- Use a nondirective, facilitative approach. Allow learners to arrive at solutions by themselves.
- Use probes, questions, and rephrasing to help learners analyze the case on their own.
- If learners are reluctant to respond to questions, use your list of prompting questions. Examples include, "What are some possibilities for action here?" "What theories does this problem illustrate?" "What are the consequences of this action?"
- Occasionally break the larger group into smaller groups to work on specific exercises or solve a specific problem.
- Write critical points on the board or on a flip chart.
- If the case has a real-life conclusion or you know of some additional information about the case, share that with the class at the end.
- At the end of the case study, review the case study's objectives. Ask students, "Did we do that?" or "Are you able to do that after this case study?"
- At the end of the case study, summarize the main points and discuss how information learned in previous sessions relates to the case study.

C. Demonstration

A demonstration is a prepared presentation that shows how to perform a skill or follow a procedure. It is accompanied by appropriate oral and visual explanations, illustrations, and questions. The basic process is show, tell, practice.

1. Advantages of demonstrations

- Is concrete.
- Provides learners firsthand contact with what is being described in the lesson.
- Can clarify points expressed during a lesson.
- Promotes learning because showing and telling are better than merely telling.
- Appeals to a variety of senses and learning styles.

2. Disadvantages of demonstrations

   - Requires careful planning.
   - Can be time consuming.
   - Might require assembling of equipment, supplies, materials.
   - Might be difficult for all learners to see and hear if the group is large.

3. Tips for effective demonstrations

   - Explain why the skill is being learned.
   - Break the skill down into steps.
   - Keep directions simple.
   - Allow time for questions.
   - Let as many learners as possible practice the skill.
   - Correct errors in performing the skill immediately and tactfully.
   - At the end, summarize the main steps in the skill.

D. Role playing

Role playing is a spontaneous portrayal of a situation, condition, or circumstance by trainees.

1. Advantages of role playing

   - Provides a relatively safe environment for trying out new skills.
   - Is an active learning technique.
   - Can be used in small or large groups.
   - Can create new insights as the trainees are put in new situations.
   - Increases the likelihood of transfer of knowledge from the classroom to the job.

2. Disadvantage of role playing

   - Some learners may be anxious about role playing.

3. Tips for effective role playing

   - Use volunteers; never force someone to role play.
   - Carefully explain how to do the role play; make sure everyone understands their role.
   - Try real-life problems generated by participants themselves.
   - While the role play is happening, move around and observe whether everyone is acting out their role appropriately.
   - Allow the action to proceed only so long as it contributes to understanding (10–15 minutes).

- Discuss the role play afterward. Ask learners about any insights they gained, how they might use this on the job.

E. Panel discussion

Panel discussions are an interchange of ideas among panelists (typically, three to six) coordinated by a moderator. The panel discussion usually provides an opportunity for trainees to comment or ask questions.

1. Advantages of panel discussions

   - Provides an opportunity to gain knowledge about many sides of a complex issue.
   - Adapts well to any size group.

2. Disadvantages of panel discussions

   - Is more of a passive activity for learners than an active one.
   - Requires a skilled and knowledgeable moderator.
   - Moderator must make sure that panelists stick to timelines so that all panelists have time to talk.

3. Tips for effective panel discussions

   - Select panel members who hold different viewpoints about the topic or can provide different insights about an issue.
   - Panel discussions that are spontaneous (rather than scripted) are more interesting for learners.

F. Brainstorming

Brainstorming is used to stimulate creative thinking about issues, problems, and common topics. Ideas are presented quickly and continuously, without interruption or criticisms, to generate a large number of suggestions.

1. Advantages of brainstorming

   - Everyone participates.
   - In a noncritical atmosphere, many original and creative suggestions might be presented.
   - One idea can stimulate participants to think of more ideas.
   - Encourages learners to be creative.
   - Can be fun.

2. Disadvantages of brainstorming

   - Might be difficult in a large group; consider breaking into small groups.
   - Unless guided properly, criticism might occur before all ideas are presented.

- Is more effective if the group is made up of people of approximately the same training or rank.

3. Tips for facilitating effective brainstorming

- Write a specific topic or question on the board or flipchart.
- Ask the group to call out any ideas on the topic even if they seem strange or far-out.
- Write down everything on the chart or board as it is called out. Do not criticize or evaluate anything suggested during the brainstorming until the time is up.
- Limit time for the brainstorming (5–15 minutes) and ask someone to let the group know when the time is up.

G. Practice Exercises

Practice exercises allow learners to practice performing a task such as solving a statistical problem or drawing a graph. Real-life examples are best, and it's important to explain the steps and process clearly. A key advantage to this technique is that it reinforces learning and gives learners a chance to apply what they've learned. However, if the training group is large, it might be difficult to give effective feedback.

H. Debates

In a debate, two teams of participants defend opposite sides of an issue. Learners take turns presenting their arguments, while other learners take notes and prepare questions. Debates allow learners to look at various aspects of an issue and generates a variety of opinions. They can generate a lot of energy and discussion. If a group is large, however, some learners might not be able to participate.

V. Evaluation

Evaluation is critical to ensuring that a training program is working. It assesses the effectiveness of a program and helps to identify strengths and weaknesses. Table A.5. summarizes four types of evaluation.

Table A.5. Levels of Evaluation

Evaluation level	What is measured	Example questions addressed	Example measurement methods	When this level is measured
1. Reaction	Learners' perceptions	• What did the learners think of this training? • Was this training well organized? • Was the information helpful? • How well did the instructor present the information?	• Written questionnaires with open-ended and closed-ended questions • Interviews	• Immediately after training
2. Learning	Learners' knowledge, skills gained, attitudes modified	• Was there an increase in knowledge or skill level? • Was there a change in attitude?	• Pretest/posttest • Questionnaires • Observations • Case studies • Interviews	• Immediately after the training • 3 months after the training
3. Behavior	Application of new knowledge, skills, attitudes on work behavior	• Did work behavior change as a result of training?	• Questionnaires • Observations • Interviews • Work logs	• Several months after training (3, 6, and/or 12)
4. Results	Impact	• Was screening and diagnosis of FAS improved as a result of training?	• Research studies	• Post-training

Source: Kirkpatrick, D. L. (1996). Evaluating Training Programs: The Four Levels. San Francisco: Berret-Koehler Publishers.

A. Learner reaction (level 1 evaluation)

A learner reaction evaluation, often a survey, assesses the trainers and the training program. This type of written evaluation form is frequently used at the end of training course to see how well the training course met training needs from the learners' perspectives. This evaluation also asks learners about the trainer's instruction. Training programs should encourage comments from trainers regarding their perspectives on all issues about the training. This might include comments about the appropriateness of objectives, suggestions for alternate training techniques, and critiques on how specific learners are performing.

B. Learner knowledge (level 2 evaluation)

Several tools can be used to measure whether trainees increased their knowledge and improved their skills.

- Have learners complete a pretest and a posttest about FASD knowledge related to the learning objectives.

- Observe learners during discussions, exercises, projects, and other activities. Are they showing an increased depth of knowledge in their approach to problem solving?
- Ask learners to complete a "one-minute paper." At the end of a lesson, ask learners to respond to questions such as: "What were the main points in this lesson?" "Describe one or two ways you can apply this information in your job." "What unanswered questions do you have after this session?" Responses can be anonymous or not. The information gathered from this exercise will let course developers know what other issues might need to be addressed in future courses.
- Talk with students informally. Ask them if the course is addressing their training needs. Ask how they are applying the information.

Information gathered from these sources will be compared with results from the training needs assessment to look for indications of increased skill levels.

3. Change in learner behavior (level 3 evaluation)

- Contact learners after training—say, at 3, 6, or 12 months—to determine if they have applied what they learned to their clinical practice. Information could be gathered through mail questionnaires, e-mail questionnaires, or telephone interviews.
- Gather information about whether referrals for diagnosis have increased or whether diagnoses of FAS have increased in your area. Although the increase might not establish firm evidence of the success of an educational event, it provides valuable information over time.
- Talk with learners at subsequent FASD educational events. Ask how they have incorporated what they learned at previous FASD educational events to their clinical practice. Inquire what was easy to transfer to practice and what was not and why.
- Ask learners to keep a log of persons they have referred for referral and diagnosis.

Resources for Cultural Competency

- *Cultural Competence Resources for Health Care Providers*
  U.S. Department of Health and Human Services
  Health Resources and Services Administration (HRSA)
  http://www.hrsa.gov/culturalcompetence/

- *Tool for Assessing Cultural Competence Training*
  Association of American Medical Colleges (AAMC)
  http://www.aamc.org/meded/tacct/start.htm

- *Cultural Competence Education for Medical Students*
  Association of American Medical Colleges (AAMC)
  http://www.aamc.org/meded/tacct/culturalcomped.pdf

Growth Charts

2000 CDC Growth Charts: United States
National Center for Health Statistics
Centers for Disease Control and Prevention
http://www.cdc.gov/growthcharts/
Includes links to background information, frequently asked questions, growth charts, data tables, educational materials, computer programs, reports, and related links.

Clinical Growth Charts
http://www.cdc.gov/nchs/about/major/nhanes/growthcharts/clinical_charts.htm

Individual Growth Charts

- Infants, birth to 36 months
- Children and Adolescents, 2 to 20 years
- Preschoolers, 2 to 5 years

http://www.cdc.gov/nchs/about/major/nhanes/growthcharts/charts.htm

World Health Organization (WHO) Child Growth Standards
http://www.cdc.gov/growthcharts/who_standards.htm

FASD Regional Training Centers Contact Information

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900 17th St., NW
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Washington, D.C. 20006
Phone: 202-785-4585
Fax: 202-466-6456
Website: http://www.nofas.org/

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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
1600 Clifton Rd., Mail-Stop E-86
Atlanta, GA 30333
Phone: 404-498-3913
E-mail: FASInquiries@cdc.gov
Website: http://www.cdc.gov/ncbddd/fas

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: http://www.fasdcenter.samhsa.gov

SAMHSA Center for Substance Abuse Prevention (CSAP)
Website: http://prevention.samhsa.gov

SAMHSA Substance Abuse Treatment Facility Locator
Website: http://dasis3.samhsa.gov/

National Institute on Alcohol Abuse and Alcoholism (NIAAA)
5635 Fishers Ln, MSC 9304
Bethesda, MD 20892
Phone: 301-443-3860
E-mail: niaaaweb-r@exchange.nih.gov
Web site: http://www.niaaa.nih.gov

National Organization on Fetal Alcohol Syndrome (NOFAS)
900 17th St, NW, Suite 910
Washington, DC 20006
Phone: 202-785-4585; 1-800-66-NOFAS
E-mail: information@nofas.org
Website: http://www.nofas.org
Note: NOFAS has a directory of national and state resources:
http://www.nofas.org/resource/directory.aspx

The Arc of the United States
1010 Wayne Ave., Suite 650
Silver Spring, MD 20910
Phone: 301-565-3842
E-mail: info@thearc.org
Website: http://www.thearc.org

American College of Obstetricians and Gynecologists (ACOG)
409 12th St., SW, P.O. Box 96920
Washington, DC 20090-6920
Phone: 202-638-5577
Website: http://www.acog.org

March of Dimes
1275 Mamaroneck Ave.
White Plains, NY 10605
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