Understanding Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders

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Learning objectives

This workshop is designed to help you:

- Discuss fetal alcohol syndrome and fetal alcohol spectrum disorders.
- Assess the prevalence of fetal alcohol syndrome and fetal alcohol spectrum disorders.
- Analyze potential risk factors and characteristics of fetal alcohol syndrome and fetal alcohol spectrum disorders.
- Summarize appropriate services for fetal alcohol spectrum disorders patients and their families.
- Apply prevention and treatment methods related to alcohol exposed related disorders.
- Examine implications of future research efforts.

Fetal alcohol syndrome

According to the Centers for Disease Control (CDC), one of the most severe effects of drinking during pregnancy is fetal alcohol syndrome (FAS). FAS is the leading known preventable cause of mental retardation and is one of the leading known preventable cause of birth defects. If a woman drinks alcohol during her pregnancy, her baby can be born with FAS, an incurable, lifelong condition that causes a variety of physical and mental disabilities.

Fetal alcohol syndrome (FAS) or fetal alcohol syndrome is a pattern of physical and mental defects that can develop in a fetus in association with high levels of alcohol consumption during pregnancy. Alcohol crosses the placental barrier and can stunt fetal growth or weight, create distinctive facial stigmata, damage neurons and brain structures, which can result in intellectual disability and other psychological or behavioral problems, and also cause other physical damage.

FAS is primarily characterized by:

- Abnormal facial features.
- Growth deficiencies.
- Central nervous system (CNS) problems.

People with FAS might have problems with:

- Learning.
- Memory.
- Attention span.
- Communication.
- Vision.
- Hearing.
- A combination of these.

These problems often lead to difficulties in school as well as problems getting along with others. FAS is a permanent condition with no known cure at present. FAS affects every aspect of an individual’s life and the lives of his or her family or caregivers.

History of Festal alcohol syndrome

The earliest recorded observation of possible links between maternal alcohol use and fetal damage was made in 1899 by Dr. William Sullivan, a Liverpool prison physician who noted higher rates of stillbirth for 120 alcoholic female prisoners than their sober female relatives; he suggested the causal agent to be alcohol use. This contradicted the predominating belief at the time that heredity caused intellectual disability, poverty, and criminal behavior, which contemporary studies on the subjects usually concluded. A case study by Henry H. Goddard of the Kallikak family which was popular in the early 1900’s represents this earlier perspective, though later researchers have suggested that the Kallikaks almost certainly had FAS. General studies and discussions on alcoholism throughout the mid-1900s were typically based on a heredity argument.

Prior to fetal alcohol syndrome being specifically identified and named in 1973, a few studies had noted differences between the children of mothers who used alcohol during pregnancy or breast-feeding and those who did not, but identified alcohol use as a possible contributing factor rather than heredity.

Fetal Alcohol Syndrome was named in 1973 by two dysmorphologists, Drs. Kenneth Lyons Jones and David Weyhe Smith of the University of Washington Medical School in Seattle, United States. They identified a pattern of “craniofacial, limb, and cardiovascular defects associated with prenatal onset growth deficiency and developmental delay” in eight unrelated children of three ethnic groups, all born to mothers who were alcoholics. The pattern of malformations indicated that the damage was prenatal. News of the discovery shocked some, while others were skeptical of the findings.

Dr. Paul Lemoine of Nantes, France had already published a study in a French medical journal in 1968 about children with distinctive features whose mothers were alcoholics and in the U.S., Christy Ulleland and colleagues at the University of Washington Medical School had conducted an 18-month study in 1968–1969 documenting the risk of maternal alcohol consumption among the offspring of 11 alcoholic mothers. The Washington and Nantes findings were confirmed by a research group in Gothenburg, Sweden in 1979. Researchers in France, Sweden, and the United States were struck by how similar these children looked, though they were not related, and how they behaved in the same unfocused and hyperactive manner.

Within nine years of the Washington discovery, animal studies, including non-human monkey studies carried out at the University of Washington Primate Center by Dr. Sterling Clarren, had confirmed that alcohol was a teratogen. By 1978, 245 cases of FAS had been reported by medical researchers, and the syndrome began to be described as the most frequent known cause of intellectual disability.
While many syndromes are eponymous (i.e. named after the physician first reporting the association of symptoms), Dr. Smith named FAS after the causal agent of the symptoms. He reasoned that doing so would encourage prevention, believing that if people knew maternal alcohol consumption caused the syndrome, then abstinence during pregnancy would follow from patient education and public awareness. Nobody was aware of the full range of possible birth defects from FAS or its prevalence rate at that time, but admission of alcohol use during pregnancy can feel stigmatizing to birth mothers and complicate diagnostic efforts of a syndrome with its preventable cause in the name.

Over time, as subsequent research and clinical experience suggested that a range of effects (including physical, behavioral, and cognitive) could arise from prenatal alcohol exposure, the term Fetal Alcohol Spectrum Disorder (FASD) was developed to include FAS as well as other conditions resulting from prenatal alcohol exposure. Currently, FAS is the only expression of prenatal alcohol exposure defined by the International Statistical Classification of Diseases and Related Health Problems and assigned ICD-9 and diagnoses.

With the recent revisions to the DSM, many groups advocated strongly for the inclusion of FAS, with the belief that if FASD appeared in the DSM-5, those affected would be more likely to have the ability to receive appropriate services. Unfortunately, the fifth edition of the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders did not approve for FASD to be included as an official mental health diagnosis. As most people know who have been involved with the struggle for respect for individuals with an FASD, often the most debilitating part of the disability is the mental health challenges that seem to be a part of just about everyone’s experience. Many years ago, several leaders in the FASD field identified that to get the services and supports needed, FASD in some shape or form needed to appear not only as a medical diagnosis but also as a diagnosis in the psychiatrist’s “bible”, also known as the DSM 5. Despite a lot of incredibly hard work from many people across the country, FASD, as we know it, isn’t in the main part of the newly revised manual. However, there is some very good and hopeful news: Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) will appear in the DSM 5 Appendix. While individuals advocated that the majority of people with FASD were diagnosed with a mental health disorder later in life and that inclusion of FASD as an official diagnosis would help obtain proper services, the APA argues that not all with FASD have a mental health disorder and those who do, are diagnosed with disorders that exist as their own official mental health diagnosis among those provided by the DSM-5.

Research

In recent decades, numerous studies have been conducted and have helped to further our understanding of FAS and other FASDs. One study in particular conducted by the National Survey of Family Growth (NSFG) focused on the number and characteristics of women in the United States who are at risk for an alcohol-exposed pregnancy. Their findings included:

- An estimated 2 million non-pregnant women in the United States (or 1 in 30) were at risk for an alcohol-exposed pregnancy in the month before they were interviewed, including more than 600,000 women who were binge drinking. These women are therefore at risk of having children born with birth defects and developmental disabilities known as fetal alcohol spectrum disorders. Alcohol use during pregnancy can also cause loss of the pregnancy (such as miscarriage and stillbirth), as well as prematurity (early birth), and sudden infant death syndrome (SIDS).
- While the study looked at several demographic (such as age, race, ethnicity, and marital status) and behavioral characteristics (such as number of sex partners, cigarette smoking, and marijuana use), women’s plans for pregnancy were the biggest predictor of risk.
- Women who said they were trying to get pregnant by not using contraception (birth control) were at increased risk for an alcohol-exposed pregnancy because they continued to drink even after they stopped using contraception.
- Other characteristics such as number of sex partners, age, and education were not consistently associated with alcohol-exposed pregnancy risk.

Implications of these findings

- These findings stress the importance of preventing alcohol use during pregnancy, including before a woman knows she is pregnant. This is because many women, including those who are intending to become pregnant, might not be aware of their pregnancy until several weeks to months after conception.
- Women often continue to drink alcohol even after they have stopped using contraception. This means that if they get pregnant, they will be exposing their developing baby to alcohol before realizing they are pregnant.
- Many women could benefit from interventions that try to reduce the risk of an alcohol-exposed pregnancy by changing drinking behaviors and using contraceptives.
- Messages about the risks of alcohol use during pregnancy should be discussed with women before they realize they are pregnant; these messages should be included in other preconception care and women’s health efforts.
- There is a urgent need for wider implementation of prevention programs and policy approaches that can reduce the risk of this serious public health problem.

Fetal alcohol spectrum disorders

The CDC also notes that prenatal exposure to alcohol can cause a range of disorders, known as fetal alcohol spectrum disorders (FASDs). Fetal alcohol spectrum disorders is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects include physical, mental, behavioral and learning disabilities with possible lifelong implications.

The term FASDs is not intended for use as a clinical diagnosis. Neither fetal alcohol syndrome nor fetal alcohol spectrum disorders is listed in the American Psychiatric Associations Diagnostic and Statistical Manual but exists as an Axis III diagnosis for mental health professionals.

FASDs include FAS as well as other conditions in which individuals have some, but not all, of the clinical signs of FAS. Three terms most often used are fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). The term fetal alcohol effects has been used to describe behavioral and cognitive problems in children who were prenatally exposed to alcohol, but who do not have the typical diagnostic features of fetal alcohol syndrome. In 1996, the Institute of Medicine replaced fetal alcohol effects with the terms alcohol-related neurodevelopment disorder and alcohol-related birth defects. Children with ARND might have functional or mental problems linked to prenatal alcohol exposure. These include behavioral or cognitive abnormalities or a combination of both. They also might have physical problems with the heart, kidneys, bones, and hearing.

All fetal alcohol spectrum disorders are 100 percent preventable if a woman does not drink alcohol while she is pregnant.
Prevalence

The reported rates of FAS vary widely. These different rates depend on the population studied and the surveillance methods used. CDC studies show FAS rates ranging from 0.2 to 1.5 per 1,000 live births in different areas of the United States. Other FASDs are believed to occur approximately three times as often as FAS.

Other studies reflecting a variety of ascertainment methodologies have produced estimates ranging from 0.5 to 2.0 cases per 1,000 live births. Such rates are comparable with or are above other common developmental disabilities such as Down syndrome or spina bifida. Using the CDC estimates, among the approximately 4 million infants born each year, an estimated 1,000 to 6,000 will be born with FAS. Studies of particularly vulnerable populations yield prevalence estimates that far exceed those of other common disabilities.

Some cultures, Native Americans and other minorities have been documented to have rates as high as three to five children with fetal alcohol syndrome per 1,000 births. Available data also suggests that poverty is strongly associated with women’s alcohol use before and during pregnancy, leading to an excess of children with FAS in impoverished groups.

The magnitude of the problem is even greater when the risk of FAS is considered by looking at the rate of alcohol-exposed pregnancies. In 1999, over half of all U.S. women of childbearing age reported alcohol consumption in the past month. The large majority of these women drank only occasionally, but 15 percent could have been classified as moderate or heavy drinkers. During that same period, 13 percent of women reported consuming five or more drinks on one occasion (binge drinking) in the past month. Given that nearly half of all U.S. pregnancies are unintended, and that millions of fertile women are sexually active while not using adequate contraception, it is estimated that 2 percent of women could be at risk for an alcohol-exposed pregnancy annually.

Risk factors

One common misconception is that FASD is associated with certain ethnic, cultural, or racial backgrounds. Instead, available data suggest that risk factors for prenatal alcohol exposure include:

- Higher maternal age.
- Lower education level.
- Prenatal exposure to cocaine and smoking.
- Custody changes.
- Lower socioeconomic status.
- Paternal drinking and drug use at the time of pregnancy.
- Reduced access to prenatal and postnatal care and services.
- Inadequate nutrition and a poor developmental environment (e.g., stress, abuse, neglect).

In one study of birth mothers of children with full FAS, the researchers found that the mothers came from diverse racial, cultural, educational, and economic backgrounds. They were often beset with untreated or undertreated behavioral health concerns, were often socially isolated, were often victims of physical or emotional abuse and they often had histories of severe childhood sexual abuse.

The most important risk factor for development of FASD is related to:

- High blood-alcohol concentration.
- The timing of exposure during fetal development.
- The pattern of consumption, i.e., binge drinking (four or more drinks per occasion).
- The frequency of use.

Although, at present, there seems to be no definite threshold of exposure, there appears to be a dose-response relation. The greater amount of alcohol consumed during the course of a pregnancy, the higher the probability of the development of FASDs.

Below is a CDC chart showing patterns of binge drinking among children-bearing age women in the United States.

Characteristics of children with FAS and other FASDs

FAS is the severe-end of a spectrum of effects that can occur when a woman drinks during pregnancy. Fetal death is the most extreme outcome. FAS is a disorder characterized by abnormal facial features and growth and central nervous system (CNS) problems. The facial feature issue is due to the fact that alcohol is a mid-line teratogen. If a pregnant woman drinks alcohol but her child does not have all of the symptoms of FAS, it is possible that her child has another FASD, such as alcohol-related neurodevelopmental disorder (ARND). Children with ARND do not have full FAS but might demonstrate learning and behavioral problems caused by prenatal exposure to alcohol. Examples of these problems are difficulties with mathematical skills, difficulties with memory or attention, poor school performance, and poor impulse control and/or judgment.

Children with FASDs might have the following characteristics or exhibit the following behaviors:

- Small size for gestational age or small stature in relation to peers.
- Facial abnormalities such as small eye openings.
- Poor coordination.
- Hyperactive behavior.
- Learning disabilities.
Developmental disabilities (e.g., speech and language delays).
- Mental retardation or low IQ.
- Problems with daily living.
- Poor reasoning and judgment skills.
- Sleep and sucking disturbances in infancy.

Children with FASDs are at risk for:
- Psychiatric problems.
- Criminal behavior.
- Unemployment.
- Incomplete education.

These are secondary conditions that an individual is not born with but might acquire as a result of FAS or a related disorder. These conditions can be very serious, but there are protective factors that have been found to help individuals with FASDs. For example, a child who is diagnosed early in life can be placed in appropriate educational classes and given access to social services that can help the child and his or her family. Children with FASDs who receive special education are more likely to achieve their developmental and educational potential. In addition, children with FASDs need a loving, nurturing, and stable home life to avoid disruptions, transient lifestyles, or harmful relationships. Children with FASDs who live in abusive or unstable homes or who become involved in youth violence are much more likely than those who do not have such negative experiences to develop secondary conditions.

Mechanism of action of alcohol on fetal development

Alcohol is able to permeate the placenta and enter fetal circulatory system, thereby causing developmental abnormalities. Ethanol impairs placental blood flow to the fetus by constricting blood vessels which is known to induce hypoxia and fetal malnutrition. Alcohol rapidly crosses the placenta and blood-brain barrier of the fetus. The damage produced depends on gestational period, dosage, and chronicity of abuse. There are many proposed, but not yet proven, mechanisms of ethanol. These include altered neural crest cell migration and increased neural crest cell death or general cell death by superoxide radical lysis of cells and mitochondrial cell dysfunction. These in turn, may inhibit growth factors regulating cell proliferation and survival; effect glial cells, development of neurotransmitter systems and cell adhesion; and alter development regulation of gene expression.

Continuum of effects that can result from maternal prenatal consumption of alcohol

Most certainly, the single most common effect seen from fetal alcohol exposure is an increase in spontaneous abortions, commonly known as miscarriages. Babies can also be born at low birth weight, birth length, and with a small head circumference resulting from prenatal alcohol exposure. Some of the other effects caused by maternal drinking range from an increase in the number of stillbirths, decreased Apgar scores at birth, an increase in the number of birth defects, increased developmental delays, decreased IQ scores, to fetal alcohol syndrome and an increased death rate. (Creative Consultants Inc.)

The presence of birth defects is dependent on:
- Dosage (how much is used).
- Timing of exposure (when is it used?).
- Individual factors of mother and child.
- Genetic factors.
- Nutritional factors.
- Metabolic factors.

As reported earlier, alcohol is a teratogen, as are a number of other things including, crack cocaine, heroin, X-rays, etc. The dosage of the exposure to a teratogen is important. Usually, the less exposure, the better off the fetus will be in the long term. The timing of the teratogenic exposure is of vital importance. Prenatal exposure to alcohol causes different problems at different times, dependent strictly upon the timing of the exposure.

The individual factors of the mother and exposed fetus are also important and one of the reasons why researchers have not been able to determine when and how much would be safe to drink. Since these individual factors cannot be determined, the only way to prevent FAS and other FASDs is for a pregnant woman to abstain from the use of all alcoholic beverages during her pregnancy.

Secondary conditions associated with FAS

The CDC has noted a number of secondary conditions that have been found to be associated with FAS:

**Mental health problems**

Several studies have shown an increased risk for cognitive disorders, psychiatric illness, or psychological dysfunction among individuals with FAS. The most frequently diagnosed disorders are:
- Attention problems (including attention deficit/hyperactivity disorder (ADHD)).
- Conduct disorder.
- Alcohol or drug dependence.
- Depression.
- Psychotic episodes.

Other psychiatric problems, such as anxiety disorders, eating disorders, and post traumatic stress disorder, have also been reported for some patients.

**Disrupted school experience**

Children with FAS are more likely than most children to be suspended, expelled or drop out of school. Difficulty getting along with other children, poor relationships with teachers and truancy are some of the reasons that lead to their removal from the school setting. Many children with FAS remain in school but have negative experiences because of their behavioral challenges. As with many of the behavioral issues associated with FASD, prenatal exposure to alcohol is believed to disrupt proper development of the executive functioning in children.

**Trouble with the law**

Teenagers and adults with FAS are more likely than those who do not have FAS to have interactions with police, authorities, or the judicial system. Difficulty controlling anger and frustration combined with problems understanding the motives of others result in many individuals with FAS being involved in violent or explosive situations. People with FAS can be very easy to persuade and manipulate, which can lead to their taking part in illegal acts without being aware of it.

**Inappropriate sexual behavior**

Individuals with FAS are more likely than individuals who do not have FAS to exhibit inappropriate sexual behavior, such as inappropriate advances and inappropriate touching. Being a victim of violence increases the risk of participating in sexually inappropriate behavior.

**Alcohol and drug problems**

Studies suggest that more than a third of individuals with FAS have had problems with alcohol or drugs, with more than half of those requiring some form of inpatient treatment.
Dependent living and problems with employment over age 21
Adults with FAS generally have difficulty sustaining employment or living independently as productive members of their communities.

Problems with parenting
Individuals with FAS who experience some of the other problems described here are more likely to become parents compared to individuals who do not have FAS. For example, an individual who has FAS may have poor judgment and poor impulse control as a result of primary brain dysfunction. These factors, combined with a secondary condition of alcohol dependence, may result in unprotected sex and pregnancy. This can possibly lead to another generation of babies at risk of prenatal alcohol exposure.

Individuals with FAS who become parents are more likely to have a history of having lived in unstable homes, more likely to have been homeless, more likely to have run away from home, and more likely to have experienced domestic violence compared to individuals with FAS who do not become parents.

IDENTIFICATION, REFERRAL, AND DIAGNOSIS

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 day care staff, interact with a large number of children and often recognize when someone is having difficulty. Social service professionals, such as 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. 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 person and his or her family to the appropriate next step.

Referral
The referral process is initiated at the point a clinician starts to have suspicions of 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, would be most productive.

Diagnosis
At this stage, the child would be presented to a multidisciplinary team who would engage in a more thorough assessment of the child using FAS diagnostic procedures to evaluate dysmorphia and growth parameters, as well as obtain appropriate neurodevelopmental evaluation data. Once a diagnosis is made, an intervention plan would be 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 use of these guidelines. In many rural and less populated 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 setting; for example school systems could provide neurocognitive assessments.

Counselor issues related to initial identification and referral
Counselors are often reluctant to explore issues related to prenatal exposure to alcohol, especially with biological mothers and other family members. They may be fearful of the reaction they will get or fear that the child’s historian will not be willing to provide accurate information regarding fetal exposure to alcohol. Mental health professionals may have to work with a mother’s denial and shame over having possibly caused harm to their child. To get an accurate history the counselor must be able to suspend judgment and provide a safe place for the mother/caregiver/historian to provide important details.

Another issue that can keep counselors from diagnosing a child with FAS or one of the FASDs is the fear that they will “label” the child. Sadly, if the opportunity to correctly diagnose FAS is missed, years may go by before the individual is properly diagnosed and treated. In the world of FAS and FASDs, the earlier the diagnosis, interventions and treatment, the better the outcome for the child.

Diagnostic categories
The diagnosis is based, largely, on maternal history of alcohol consumption during pregnancy, abnormalities involving facial features, growth deficiency and central nervous system dysfunction. The Institute of Medicine developed the following criteria to diagnose fetal alcohol related problems.

- FAS with confirmed maternal alcohol exposure: Patients in this category have the classic triad of growth retardation, characteristic facial dysmorphology and neurodevelopmental abnormalities. This is often defined as full-blown FAS.
- FAS without confirmed maternal alcohol exposure: If the triad described in category 1 is present, a diagnosis of FAS is possible even without confirmed maternal drinking.
- Partial FAS with confirmed maternal alcohol exposure: Such patients may have only some of the characteristic facial anomalies plus...
growth retardation or central nervous system neurodevelopmental abnormalities or behavioral/cognitive abnormalities.
- FAS with confirmed maternal alcohol exposure and alcohol related birth defects: Patients in this category will have some congenital anomalies as a result of alcohol toxicity.
- FAS with confirmed maternal alcohol exposure and alcohol related neurodevelopmental disorder: Patients in this category will have evidence of central nervous system neurodevelopmental abnormalities or a complex pattern of behavioral/cognitive abnormalities, or both, but not necessarily any obvious physical changes.

## DIAGNOSTIC CRITERIA

### Dysmorphia

Human congenital malformations are referred to as dysmorphic features or dysmorphia. The CDC notes that dysmorphia occurs when normal morphogenesis is interrupted, creating a particular feature which is shaped, sized or positioned outside the normal range of development. Alcohol is a mid-line teratogen that often results in dysmorphia through interference with nerve cell development and functioning, alterations in the ability of cells to grow and survive, increased formation of cell-damaging free radicals, altered pathways of biochemical signals within cells, and altered expression of certain genes and genetic information. In short, alcohol has been shown to interfere with fetal nerve cell development and function in a variety of ways.

In first describing the dysmorphic features of FAS, Jones and colleagues focused on short palpebral fissure, maxillary hypoplasia (with prognathism), and the presence of epicanthal folds that were observed for a majority of the children described. However, other features also were noted for some patients, including altered palmar flexional crease patterns (i.e., hockeystick crease), cardiac anomalies, joint disability, overlapping fingers, ear anomalies, hemangiomas, ptosis, hypoplastic nails and pectus deformities. Over the next 30 years, additional features described included: microcephaly, short nose, smooth philtrum with thin vermilion border, cleft lip, micrognathia, protruding auricles, short or webbed neck, vertebra and rib anomalies, short metacarpal bones, menigomyelocele, hydrocephalus and hypoplastic labia majora.

Despite the heterogeneity of expression for dysmorphic features related to prenatal exposure to alcohol, core facial dysmorphia have emerged through human and animal studies. Experimental studies with a mouse model and primates indicate that the facial dysmorphia observed for individuals with FAS are the result of disturbances of cellular migration during organogenesis along the midline of the face. Using anthropomorphic measurements of all facial features, clinical researchers have confirmed the midline feature abnormalities. Studies of clinic-referred samples also support these features as discriminant for FAS. Based on these scientific findings and the extensive clinical experience of the SWG, the following facial dysmorphic features were determined to meet the dysmorphia criteria essential for FAS (based on racial norms):
- Smooth philtrum – (measured as 4 or 5 on Lip-Philtrum Guide*).
- Thin vermilion border – (measured as 4 or 5 on Lip-Philtrum Guide) (i.e., upper lip).
- Small palpebral fissures – (measured as 10th percentile according to age and racial norms).

The individual must exhibit all three characteristic facial features; however, additional features also can be present. For example, maxillary hypoplasia is often noted for individuals with FAS as well as those associated features described previously. Cross-sectional and longitudinal studies indicate that many features can change with age or development. After puberty, the characteristic facial features associated with FAS can become more difficult to detect. However, recent findings indicate that these three key features remain for the majority of individuals with FAS.

A characteristic pattern of mild facial anomalies, including small eye openings (i.e., short palpebral fissures), a thin upper lip, or flattened ridges between the base of the nose and the upper lip (i.e., a flattened philtrum) are associated with FAS.

### Services appropriate for FASD individuals and their families

The 2004 CDC Fetal Alcohol Syndrome Guidelines for Referral and Diagnosis indicates that diagnosis is never an endpoint for any individual with a developmental disability and his or her family. This is particularly true for individuals with FAS, their families, and their community. As described in the framework section, the FAS diagnosis and the diagnostic process (especially the neuropsychological assessment) are part of a continuum of care that identifies and facilitates appropriate health care, education and community services. The learning and life skills affected by prenatal exposure vary greatly among individuals, depending on the amount of alcohol exposure and the timing and pattern of exposure, as well as each individual’s current and past environment. As a result, the services needed for individuals with FAS and their families vary according to what parts of the brain have been affected, the age or level of maturation of the person, the health or functioning of the family, and the overall environment in which the person is living. Thus, service needs for any particular individual and his or her family can be quite individualistic.

Despite the required individualization in service needs, some general areas of service and specific services have been identified as helpful to people with FAS and their families. While the ideal circumstance are services and interventions that have been specifically developed for individuals with FAS and their effectiveness has been established through rigorous scientific evaluation, such programs are only now being researched and developed. Thus, most evidence for the benefit of services has been gleaned from research with other populations, clinical wisdom and family experiences. These three sources have drawn heavily from information obtained concerning risk and protective factors that have been found through systematic research, using natural history methodology, to promote positive development or reduce the incidence of negative long-term consequences of FAS (i.e., reduce secondary conditions). First, these factors will be reviewed. Then, services that are applicable to all individuals with FAS regardless of life stage will be presented. Finally, essential services appropriate for individual life stages will be presented.

### General needs

Helpful interventions should include those that stabilize home placement, strengthen the parent-child dyad, and improve parent-child interaction. One method for accomplishing this goal is to increase the understanding of the disorder by parents, teachers, law enforcement personnel and other professionals who might become involved with the affected individual. Children with FAS often need unique parenting because of their difficulty with cause-and-effect reasoning and other executive functioning skills.
Caregiver education should highlight and explain differences in the thought processes of children with FAS from typically developing children and children with other developmental disabilities. This would enable parents to avoid potentially difficult situations (e.g., avoiding overly stimulating environments) and better manage problems when they do arise. Overall, a better functioning family that results from caregiver education promotes the stable, nurturing home that has been shown to be a positive protective factor for children with FAS.

Beyond the home environment, other professionals also need increased education and information concerning FAS. Parents can facilitate this understanding by learning to become advocates for their child. Such advocacy includes both linking families with needed community resources and making sure that the child receives maximum benefit from that service. Because the myriad of service systems is confusing and inconsistent across states, families must be educated about them at the local level. The world of social and educational services can be overwhelming, confusing and inconsistent, and usually has a unique vocabulary that must be learned. Thus, it is important that along with a diagnosis, clinicians need to help caregivers in learning about available services, how to determine which services are appropriate for their child, and how to work productively with service providers.

Many prenatally exposed infants and children enter the foster or adoptive care system at an early age. A recent study estimated that the prevalence of children with FAS (or a related disorder) in the foster care system is 10 times that of the general population. However, while protective service agencies (PSAs) might have information about a child’s prenatal history, staff members are generally not knowledgeable about FAS, do not understand the impact of the child’s having FAS, or do not communicate the child’s FAS status to other service systems. As a result, foster and adoptive families are most often not educated about the long-term effects and are unprepared to meet their child’s needs. However, most PSAs require foster parents to take a specified number of educational courses annually. These courses should include education about the effects and developmental needs of the child with FAS since the majority of foster parents will encounter at least one child with FAS or a related disorder during their time as a foster parent.

The assessment process is integral to a well-developed treatment plan. As has been emphasized in these guidelines, part of the diagnostic process is a comprehensive neuropsychological assessment, not only to establish CNS abnormalities for the diagnosis, but also to develop the best treatment plan possible. Such a treatment plan minimizes risk factors for lifelong negative consequences and promotes protective factors that maximize developmental potential. Clinicians and service providers must ensure that assessments include communication and social skills, emotional maturity, verbal and comprehension abilities, language usage, and, if appropriate, referral for medication assessments. Finally, it is the responsibility of the community at large to ensure that children with disabilities, including children with FAS, have access to and are assimilated into school, recreational and social activities.

### Intervening with children and/or adolescents with fetal alcohol syndrome or alcohol-related neurodevelopmental disorders

Several organizations are working together with the CDC through a collaborative effort to identify, develop, and evaluate effective strategies for intervening with children with FAS/ARND and their families. Through these interventions, researchers are trying to help children with FAS/ARND develop to their full potential, prevent secondary conditions, and provide education and support to caregivers and families.

**Funded projects include:**

**Marcus Institute, Atlanta, GA**
This intervention focuses on behavioral regulation training (BRT) as a readiness-for-learning strategy, and math skills for improving cognition. BRT teaches parents ways to modify the child’s environment to reduce excess stimulation, use appropriate social reinforcement and communicate choices rather than commands. All children in the study population diagnosed with FAS or ARND and their families participate in the BRT and are taught self-awareness, decision-making and verbalization of situations and actions. In addition, intervention participants receive individualized math skills training, a common area of significant disability for children with FAS/ARND. The intervention is designed for children ages 3 through 9.

**University of Washington, Seattle, WA**
The purpose of this project is to explore two intervention models for school-age children. One consists of an individualized, supportive, behavioral consultation intervention for school-age children (ages 5 through 11) with FAS or ARND. Consultation includes FAS education, emotional/practical support, teaching child management strategies specific to children with FAS/ARND, advocacy assistance and school consultation. The second intervention is a school-based social communication intervention provided directly to children with FAS/ARND. This intervention targets critical deficits in social communication and peer relations and is designed to teach children (aged 8 through 12 years) how to use an interactive checklist to guide them through resolution of peer conflicts. An intervention and a control group will be compared using pre- and post-test measures, with post-tests occurring at the conclusion of the intervention and at a nine month follow-up.

**University of Oklahoma Health Services Center, Oklahoma City, OK**
This project uses parent child interaction therapy (PCIT) to intervene with parents and their children (ages 2 through 7) who have been diagnosed with FAS or ARND. The treatment group receives 90-minute group sessions once a week for 14 weeks. Behavioral specialists conduct group sessions with parents to teach them appropriate and effective behaviors and interaction techniques. Parent-child interactions are observed and individualized guidance is provided. The control group receives standard referrals and services along with participation in a parent support group. Pre – and post-test comparisons will be made between groups at the conclusion of the intervention and at 6-, 12- and 18-month follow-ups.

**University of California, Los Angeles, CA**
This project focuses on parent-assisted social skills training, with particular attention to development of best friend relationships. Children (ages 6 through 8) receiving the intervention participate in didactic training sessions, behavior rehearsal, and coaching to reduce maladaptive behaviors and promote pro-social interaction skills. Simultaneously, parents are taught about core deficits of FAS and ARND and given the companion information to their children’s intervention. A control group receives standard community care and both groups of participants are re-evaluated at four months post-intervention.

**Children’s Research Triangle, Chicago, IL**
This intervention proposes to develop a program of neurocognitive habilitation within a systematic intervention strategy for children with prenatal alcohol exposure. The target population is children (ages 6 through 12) diagnosed with FAS or ARND, currently in the care of the Illinois welfare system. Children and their families are randomly selected into two groups. Children and families participating in the treatment group receive 12 weeks of neurocognitive habilitation and psychotherapy services, along with family education and case management services. Children and families participating in the control group will receive the current standard of care through existing community and school-based agencies. Pre – and post – measures will be analyzed for each group and post-test follow-up will occur at 12 and 24 months.
What do we know about prevention of FASDs?

FASDs are completely preventable—if a woman does not drink alcohol while she is pregnant or could become pregnant. If a woman is drinking during pregnancy, it is never too late for her to stop. The sooner a woman stops drinking, the better it will be for both her baby and herself. If a woman is not able to stop drinking, she should contact her doctor, local Alcoholics Anonymous, or local alcohol treatment center. The Substance Abuse and Mental Health Services Administration has a substance abuse treatment facility locator. This locator helps people find drug and alcohol treatment programs in their area. If a woman is sexually active and is not using an effective form of birth control, she should not drink alcohol. She could become pregnant and not know it for several weeks or more.

Mothers are not the only ones who can prevent FASDs. The father’s role is also important in helping the mother abstain from drinking alcohol during pregnancy. He can encourage her not drinking alcohol by avoiding social situations that involve drinking and by not drinking alcohol himself. Significant others, family members, schools, health and social service organizations, and communities can also help prevent FASDs through education and intervention.

Surgeon general’s advisory on alcohol use in pregnancy

In February of 2005, United States Surgeon General Richard H. Carmona released the following advisory on alcohol use in pregnancy:

Thirty-two years ago, United States researchers first recognized Fetal Alcohol Syndrome (FAS). FAS is characterized by growth deficiencies (or decreased growth), abnormal facial features (specific facial features), and central nervous system (or brain) abnormalities. FAS falls under the spectrum of adverse outcomes caused by prenatal alcohol exposure called Fetal Alcohol Spectrum Disorders (FASD). 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.

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.

What school systems should know about prevention

Students with FASD have problems receiving and processing information. They often cannot store what they learn or lack the mental capacity to use new information they have been given. While students with FASD have IQ scores that range from 29 to 140, their overall level of adaptive functioning (i.e. ability to perform daily life skills) is often much lower than would be expected.

Most students with FASD are unidentified or go misdiagnosed as most people with FASD do not have the characteristic features associated with fetal alcohol syndrome. The majority of students with FASD are not significantly developmentally disabled, and they can be articulate and skilled at performing specific tasks.

Despite laws in every state that make it illegal for anyone under the age of 21 to purchase or possess alcohol, young people report that alcohol is easy to obtain. Alcohol is by far the most commonly abused substance by female adolescents with 36.5 percent (4.5 million) of girls ages 12 to 17 reporting alcohol use within the past year.

Nearly 74 percent of adults report that they began drinking alcohol before the current legal drinking age of 21. A nationwide study indicates that 60 percent of adolescents ages 12 to 17 who drink are binge drinkers (5 or more drinks in a row).

Drinking predisposes young adults to risky sexual behaviors. A study of adolescent drinkers found that problem drinkers are more likely than other drinkers to be sexually active, to have a greater number of partners, and to initiate sexual activity at younger ages. Among the reported 34 percent of currently sexually active students nationwide, 25 percent had drunk alcohol or used drugs before their last sexual intercourse.

In February 2005, the U.S. surgeon general issued an advisory on alcohol use in pregnancy to raise public awareness about this important health concern. 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.

To reduce prenatal alcohol exposure, prevention efforts should target not only pregnant women who are currently drinking, but also women who could become pregnant, are drinking at high-risk levels and are having unprotected sex.
School Systems can help prevent FASD by:
- Including information about FASD in health and/or human development course curricula.
- Providing alcohol-free recreation and entertainment opportunities for young adults.
- Supporting FASD peer-education programs.
- Encouraging student participation in FASD or substance abuse-related community coalitions to meet required community service hours for graduation.

Common challenges for educators who teach students with FASD include:
- Hyperactivity, impulsivity, attention and memory deficits.
- Inability to complete tasks, disruptiveness.
- Poor social skills.
- Need for constant supervision.
- Disregard for rules and authority.

Successful strategies for educating children with FASD include:
- Using concrete, hands-on learning methods.
- Establishing structured routines.
- Keeping instructions short and simple.
- Providing consistent and specific directions.
- Repeating tasks again and again.
- Providing constant supervision.

According to Evensen and Lutke (1997), there are some suggested strategies to working with individuals with FASD:

1. Concrete – Individuals with FASD do well when people talk in concrete terms, do not use words with double meanings, or idioms. Because their social-emotional understanding is far below their chronological age, it helps to “think younger” when providing assistance and giving instructions.

2. Consistency – Because of the difficulty individuals with FASD experience trying to generalize learning from one situation to another, they do best in an environment with few changes. This includes language. For example, teachers and parents can coordinate with each other to use the same words for key phases and oral directions.

3. Repetition – Individuals with FASD have chronic short term memory problems; they forget things they want to remember as well as information that has been learned and retained for a period of time. In order for something to make it to long term memory, it may simply need to be re-taught and re-taught.

4. Routine – Stable routines that don’t change from day to day will make it easier for individuals with FASD to know what to expect next and decrease their anxiety, enabling them to learn.

5. Simplicity – Remember to Keep it Short and Sweet (KISS method). Individuals with FASD are easily over-stimulated, leading to “shutdown” at which point no more information can be assimilated. Therefore, a simple environment is the foundation for an effective school program.

6. Specific – Say exactly what you mean. Remember that individuals with FASD have difficulty with abstractions, generalization, and not being able to “fill in the blanks” when given a direction. Tell them step by step what to do, developing appropriate habit patterns.

7. Structure – Structure is the “glue” that makes the world make sense for an individual with FASD. If this glue is taken away, the walls fall down! An individual with an FASD achieves and is successful because their world provides the appropriate structure as a permanent foundation.

8. Supervision – Because of their cognitive challenges, individuals with FASD bring a naiveté to daily life situations. They need constant supervision, as with much younger children, to develop habit patterns of appropriate behavior.

Tracking Fetal Alcohol Syndrome (FAS)

CDC is working with states to develop FAS tracking systems. It is important to know how many people have FAS in order to understand and identify vulnerable populations; target prevention and treatment resources; and evaluate the strengths and limitations of various prevention, intervention, and treatment strategies.

The current reported prevalence of FAS rates is likely a reflection of variation in study populations, case definition, case ascertainment sources, and surveillance methodologies among studies. Older CDC studies that relied on general birth defects or developmental disability surveillance systems not specifically designed for FAS estimated a prevalence of 0.5 – 2.0 cases of FAS per 1,000 live births. Using multiple-source, record-based methods, studies by a network of states, referred to as Fetal Alcohol Syndrome Surveillance Network or FASSNet, found prevalence estimates of 0.3 – 1.5 cases of FAS per 1,000 live births in certain areas in the United States.

TREATMENT APPROACHES

There is no cure for FAS but treatment is possible. Because of central nervous system damage, symptoms, secondary disabilities, and needs vary widely by individual, there is no one treatment type that works for everyone. The following examples are types of interventions to consider.

Medical interventions

Traditional medical interventions (i.e., psychoactive drugs) are frequently tried on those with FAS because many FAS symptoms are mistaken for or overlap with other disorders, most notably ADHD.

Behavioral interventions

Traditional behavioral interventions are predicated on learning theory, which is the basis for many parenting and professional strategies and interventions. Along with ordinary parenting styles, such strategies are frequently used by default for treating those with FAS, as the diagnoses Oppositional Defiance Disorder (ODD), Conduct Disorder, Reactive Attachment Disorder (RAD), etc. often overlap with FAS (along with ADHD), and these are sometimes thought to benefit from behavioral interventions. Frequently, a patient’s poor academic achievement results in special education services, which also utilizes principles of learning theory, behavior modification, and outcome-based education.

Because the “learning system” of a patient with FAS is damaged, however, behavioral interventions are not always successful or not successful in the long run, especially because overlapping disorders frequently stem from or are exacerbated by FAS. Kohn (1999) suggests that a rewards-punishment system in general may work somewhat in the short term but is unsuccessful in the long term because that approach fails to consider content (i.e., things “worth” learning), community (i.e., safe, cooperative learning environments), and choice (i.e., making choices versus following directions). While these elements are important to consider when working with FAS and have some usefulness in treatment, they are not alone sufficient to promote better outcomes. Kohn’s minority challenge to behavioral interventions does illustrate the importance of factors beyond learning theory when trying to promote improved outcomes for FAS, and supports a more multi-model approach that can be found in varying degrees within the advocacy model and neurobehavioral approach.

Developmental framework

Many books and handouts on FAS recommend a developmental approach, based on developmental psychology, even though most do not specify it as such and provide little theoretical background. Optimal human development generally occurs in identifiable stages (e.g., Jean Piaget’s theory of cognitive development, Erik Erikson’s stages of psychosocial development, John Bowlby’s attachment framework, and other developmental stage theories). FAS interferes with normal development, which may cause stages to be delayed, skipped, or immaturely developed. Over time, an unaffected child can
negotiate the increasing demands of life by progressing through stages of development normally, but not so for a child with FAS.

By knowing what developmental stages and tasks children follow, treatment and interventions for FAS can be tailored to helping a patient meet developmental tasks and demands successfully. If a patient is delayed in the adaptive behavior domain, for instance, then interventions would be recommended to target specific delays through additional education and practice (e.g., practiced instruction on tying shoelaces), giving reminders, or making accommodations (e.g., using slip-on shoes) to support the desired functioning level. This approach is an advance over behavioral interventions, because it takes the patient’s developmental context into account while developing interventions.

Advocacy model
The advocacy model takes the point of view that someone is needed to actively mediate between the environment and the person with FAS. Advocacy activities are conducted by an advocate (for example, a family member, friend, or case manager) and fall into three basic categories. An advocate for FAS: (1) interprets FAS and the disabilities that arise from it and explains it to the environment in which the patient operates, (2) engenders change or accommodation on behalf of the patient, and (3) assists the patient in developing and reaching attainable goals.

The advocacy model is often recommended, for example, when developing an Individualized Education Program (IEP) for the patient’s progress at school.

Future implications
Empirical evidence has helped to develop services for those impacted by FAS. However, there is still much to learn. Reviewing significant findings of various studies can help lay the groundwork for future research studies and light the way in which direction such studies should focus their attention.

Streissguth and O’Malley (2000), among other researchers, have noted poor neuropsychiatric outcomes associated with FASD, particularly in terms of maladaptive behavior and mental illness, which complicate treatment. In young adults, PAE is also associated with alcohol problems, as well as increased psychiatric disorders and traits.

O’Connor et al (2002) noted very high rates of psychiatric disorders among children with PAE, with 87 percent of their sample meeting the criteria for a psychiatric disorder; 61 percent for mood disorder; 35 percent for bipolar disorder and 26 percent for major depressive disorder. Furthermore, even among six-year-olds, PAE is associated with depressive symptoms, particularly in girls.

In one of the first studies on secondary disabilities in Canadian adults with FASD, Clark et al (2004) tested 62 individuals (mean age of 22 years) living in British Columbia. The team of researchers found that almost all of the participants (92 percent) had a mental health disorder diagnosis. Diagnoses included ADHD (65 percent), depression (45 percent) and panic disorder (21 percent). Post-traumatic stress disorder, obsessive compulsive disorder, oppositional defiant disorder and bipolar disorder were also reported.

Individuals with PAE have been shown to exhibit maladaptive behaviors such as impulsivity, teasing/bullying, dishonesty (lying, cheating and stealing), avoiding school or work, intentional destruction of property, sexual inappropriateness, physical aggression and self-injury. FASD has also been linked to behavior problems and delinquency in adolescents, as well as problems related with alcohol and drug use. Nash et al (2006) found that alcohol-exposed children displayed higher rates of problematic behaviors than children with attention-deficit hyperactivity disorder (ADHD), particularly in delinquent behaviors such as cruelty, bullying, lying or cheating, and stealing.

An understanding of the developmental framework would presumably inform and enhance the advocacy model, but advocacy also implies interventions at a systems level as well, such as educating schools, social workers, and so forth on best practices for FAS. However, several organizations devoted to FAS also use the advocacy model at a community practice level as well.

Neurobehavioral approach
The neurobehavioral approach focuses on the neurological underpinnings from which behaviors and cognitive processes arise. It is an integrative perspective that acknowledges and encourages a multi-modal array of treatment interventions that draw from all FAS treatment approaches. The neurobehavioral approach is a serious attempt at shifting single-perspective treatment approaches into a new, coherent paradigm that addresses the complexities of problem behaviors and cognitions emanating from the CNS damage of FAS.

The neurobehavioral approach’s main proponent is Diane Malbin, MSW, a recognized speaker and trainer in the FASD field, who first articulated the approach with respect to FASD and characterizes it as “Trying differently rather than trying harder.” The idea to try differently refers to trying different perspectives and intervention options based on effects of the CNS damage and particular needs of the patient, rather than trying harder at implementing behavioral-based interventions that have consistently failed over time to produce improved outcomes for a patient. This approach also encourages more strength-based interventions, which allow a patient to develop positive outcomes by promoting success linked to the patient’s strengths and interests.

Furthermore, 97 percent of children with fetal alcohol exposure lacked guilt after misbehaving. In a recent study conducted in Alberta, young children with FASD (four to eight years of age) were found to lie more often than typically developing children. In a large-scale study of youth with FASD living in British Columbia, Fast et al (1999) found that 23 percent of youth in the criminal justice system had FASD. Streissguth et al (2000) also conducted a landmark longitudinal study on secondary disabilities among individuals with FASD. As previously noted, secondary disabilities result from the primary consequences of PAE (ie, cognitive deficits), possibly in interaction with environmental factors.

The Life History Interview, which measures common secondary disabilities, was administered to 415 individuals (six to 51 years of age) with FAS and FAE. The results were astounding – more than 90 percent of the sample had mental health problems, 49 percent of the adolescents/adults and 39 percent of the children demonstrated inappropriate sexual behavior, 14 percent of the children and more than 60 percent of adolescents/adults had disrupted school experience, and 14 percent of the children and 60 percent of adolescents/adults had been in trouble with the law. One in two of the adolescents/adults had been confined (i.e., incarcerated, admitted to inpatient mental health programs, or alcohol and drug treatment programs); and over one in three of the adolescents/adults had alcohol- and drug-related problems.

Streissguth identified five protective factors that resulted in lower rates of secondary disabilities which included living in a good quality stable home environment, infrequent changes in living arrangement, not being exposed to violence, receiving services for developmental disabilities and being diagnosed before six years of age. Three risk factors were identified that were associated with higher rates of secondary disabilities:
1. Being diagnosed with FAE rather than FAS.
2. Having an IQ above 70.
3. Higher scores on the Fetal Alcohol Behavior Scale, which measures behaviors typical of individuals with fetal alcohol exposure.

Thus, having less severe physical effects (FAE instead of FAS) and a higher rather than lower IQ were associated with a higher rate
of secondary disabilities. This counterintuitive finding may be a consequence of later diagnosis and fewer services for individuals with FAE, which increases the risk for developing secondary disabilities.

Another factor that might influence the outcome of individuals with FASD is ‘vulnerability to manipulation’. Clark et al (2002) found that 92 percent of participants were identified by their caregivers as being vulnerable to manipulation, which may have implications for affected adults involved in the legal system. For example, a vulnerable individual may be more inclined to acquiesce, provide a false confession, or have problems understanding cautions and consents. They also reported that 87 percent of the participants in their study had been victim to some form of violence, and 77 percent of individuals had experienced physical and/or sexual abuse.

From the empirical evidence provided by research studies, it is clear that children with FASD are at high risk of very poor developmental outcomes, and many questions remain to be answered. Previous studies have been conducted using many different outcome measures, diverse samples and cohorts, and varying diagnostic categories, which complicates previous findings and makes it difficult to generate general conclusions and make comparisons across studies. Research using more sound and informative methodologies, and consistent diagnostic categories and samples is crucial.

Previous research has thoroughly documented the poor outcomes of children with FASD and PAE. However, what is lacking in the majority of this research is the examination of what factors (or combination of factors) actually lead to or ‘cause’ these poor outcomes. Most children with FASD are not typically challenged by PAE and resulting CNS damage alone; many also face numerous other serious social and environmental adversities that place them at even greater risk for poor outcomes. The study by Streissguth et al (2000) provided an excellent starting point for the understanding of some of the risk and protective factors related to secondary disabilities in individuals with PAE. The interactive role of PAE, and the environmental and social factors on the many different negative outcomes in FASD, need to be examined.

Future considerations
Future research should consider addressing questions regarding how environmental factors and service utilization influence FASD, whether there are mediators and/or moderators that impact outcomes, and also whether there are other factors that make some children with FASD particularly resilient to these poor outcomes.

Further, information on the impact of the alcohol dose and binge drinking on various outcomes is critical. Connor and Streissguth (1996) suggested that further research is needed on cognitive and emotional outcomes of individuals with FASD, as well as research examining the effect of intervention techniques to best tailor treatment to the unique needs of children with FASD.

Understanding the profile of behavioral, mental health and adaptive outcomes of children diagnosed with FASD is key to improving treatment and resources for children with FASD. Such research will provide new insights into how to tailor interventions and services to address the unique needs of these children, and to ultimately improve outcomes and reduce secondary disabilities of children with FASD. Identifying protective factors that are associated with positive outcomes will guide future assessment and care of children with FASD by providing clinicians and social workers with key variables (i.e., services, early diagnosis and stable home environment) that must be carefully examined during diagnosis and assessment to enhance and/or maintain these protective factors and in turn improve outcomes. Insight into the impact of FASD on the family across various domains of family living will inform service and resource allocation to assist families in specific areas of need.

From a clinical perspective, it is essential to have more specific information on the disability and on brain function. There is the need for information on specific behavioral study of larger samples in different intervention groups. Also, increased diagnostic capacity will assist in understanding the prevalence of FASD, as well as the effect of prevention programs, which will aid in planning for future resources. Research on neurobehavioral outcomes of children diagnosed with FASD is essential to enhance services, treatment and overall life chances for these children. Furthermore, longitudinal research is needed to understand how neurobehavioral deficits may change with time and how interventions and services can be designed to address the needs of affected individuals and families.

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UNDERSTANDING FETAL ALCOHOL SYNDROME AND FETAL ALCOHOL SPECTRUM DISORDERS

Final Examination Questions

Select the best answer for each question and then proceed to www.EliteCME.com to complete your final examination.

1. Alcohol crosses the placental barrier and can stunt fetal growth or weight, create distinctive facial stigmata, damage ______ and brain structures, which can result in intellectual disability and other psychological or behavioral problems, and also cause other physical damage.
   a. Neurons.
   b. Tendons.
   c. Chromosomes.
   d. Tissue.

2. The term ______________ has been used to describe behavioral and cognitive problems in children who were prenatally exposed to alcohol, but who do not have the typical diagnostic features of fetal alcohol syndrome.
   a. Fetal alcohol syndrome.
   b. Fetal alcohol effects.
   c. Fetal alcohol disorder.
   d. Fetal alcohol neurology.

3. ___________ and other minorities have been documented to have rates as high as three to five children with fetal alcohol syndrome per 1,000 births.
   a. Native Americans.
   b. African Americans.
   c. Asian Americans.
   d. Hispanic Americans.

4. Studies have indicated that mothers of children with full FAS often had histories of severe ______________.
   a. Childhood neglect.
   b. Learning disorders.
   c. Childhood sexual abuse.
   d. Genetic mutations.

5. Alcohol is a ________, as are a number of other things including, crack cocaine, heroin, X-rays, etc.
   a. Teratogen.
   b. Stimulant.
   c. Suppressant.
   d. Sedative.

6. Prenatal exposure to alcohol is believed to disrupt proper development of the ________ functioning in children.
   a. Behavioral.
   b. Limbic.
   c. Executive.
   d. Long-term.

7. Mental health professionals may have to work with a mother’s ________ over having possibly caused harm to their child.
   a. Bias.
   b. Denial.
   c. Label.
   d. Stereotype.

8. The FAS diagnosis is based, largely, on maternal history of alcohol consumption during pregnancy, abnormalities involving facial features, growth deficiency and _________ dysfunction.
   a. Educational.
   b. Behavioral.
   c. Central nervous system.
   d. Cerebral hemisphere.

9. Human congenital malformations are referred to as ___________.
   a. Fetal mutation.
   b. Genetic adaptation.
   c. Dysmorphia.
   d. Genomorphia.

10. Helpful interventions should include those that ____________, strengthen the parent-child dyad, and improve parent-child interaction.
    a. Address physical malformations.
    b. Stabilize home placement.
    c. Identify familial cognition.
    d. Assess future medical concerns.

11. Alcohol is by far the most commonly abused substance by female adolescents with ________ percent of girls ages 12 to 17 reporting alcohol use within the past year.
    a. 15.5.
    b. 23.
    c. 36.5.
    d. 41.8.

12. Because of the difficulty individuals with FASD experience trying to generalize learning from one situation to another, they do best in an environment with ________.
    a. Few changes.
    b. Frequent changes.
    c. Common themes.
    d. Colorful patterns.

13. Traditional medical interventions (i.e., psychoactive drugs) are frequently tried on those with FAS because many FAS symptoms are mistaken for or overlap with other disorders, most notably ________.
    a. Depression.
    b. Bipolar disorder.
    c. Attachment disorder.
    d. ADHD.

14. The ________ takes the point of view that someone is needed to actively mediate between the environment and the person with FAS.
    a. Developmental approach.
    b. Advocacy model.
    c. Behavioral model.
    d. Neurobehavioral approach.
15. The neurobehavioral approach is an ____________ that acknowledges and encourages a multi-modal array of treatment interventions that draw from all FAS treatment approaches.
   a. Integrative perspective.
   b. Alternative perspective.
   c. All inclusive perspective.
   d. Intensive response perspective.

16. Streissguth and O’Malley (2000), among other researchers, have noted poor neuropsychiatric outcomes associated with FASD, particularly in terms of ___________ and mental illness, which complicate treatment.
   a. Medical conditions.
   b. Psychotropic medications.
   c. Maladaptive behavior.
   d. Language deficits.

17. Research has shown that children with fetal alcohol exposure often ___________ after misbehaving.
   a. Lacked guilt.
   b. Felt remorse.
   c. Apologized.
   d. Told the truth.

18. It is believed that having less severe physical effects (FAE instead of FAS) and a higher rather than lower IQ were associated with a higher rate of ___________.
   a. Educational success.
   b. Secondary disabilities.
   c. Interpersonal skills.
   d. Alcohol abuse.

19. Clark et al (2002) found that 92 percent of participants were identified by their caregivers as being vulnerable to ___________, which may have implications for affected adults involved in the legal system.
   a. Disease.
   b. Manipulation.
   c. Addiction.
   d. Poverty.

20. Increased diagnostic capacity will assist in understanding the prevalence of FASD, as well as the effect of ___________ programs, which will aid in planning for future resources.
   a. Prevention.
   b. Medical.
   c. Response.
   d. Family therapy.