

## **Fetal Alcohol Spectrum Disorder**

### **Course Goals & Objectives**

#### **Course Description**

Fetal Alcohol Spectrum Disorder is an asynchronous online continuing education program for physical therapists and physical therapist assistants. The course presents contemporary information about fetal alcohol spectrum disorder including sections on epidemiology, neuropathology, diagnosis, evaluation, and collaborative intervention.

#### **Course Rationale**

The purpose of this course is to present current information about fetal alcohol spectrum disorder to physical therapists and physical therapist assistants. Physical therapists and physical therapist assistants will find this information pertinent and useful when developing and implementing rehabilitation programs that address the challenges and needs specific to individuals with FASD.

#### **Course Goals & Objectives**

At the end of this course, the participants will be able to:

1. Identify risk factors associated with FASD
2. Identify neuropathology relating to FASD
3. identify the clinical signs of FASD
4. differentiate the screening and assessment tools used to identify FASD
5. recognize developmental and behavioral challenges associated with FASD
6. recognize secondary conditions associated with FASD
7. Identify the keys to successful treatment of FASD associated problems.
8. recognize the challenges faced by families affected by FASD

**Course Provider** – Innovative Educational Services

**Course Instructor** - Michael Niss, DPT

**Target Audience** – physical therapists and physical therapist assistants.

**Course Educational Level** – Introductory / intermediate

**Course Prerequisites** – None

**Method of Instruction/Availability** – Online text-based course available continuously.

**Criteria for Issuance of CE Credits** - A score of 70% or greater on the course post-test

**Continuing Education Credits** – 4 hours

**Fees** - \$39.95

**Conflict of Interest** – No conflict of interest exists for the presenter or provider of this course.

**Refund Policy** - Unrestricted 100% refund upon request. The request for a refund by the learner shall be honored in full without penalty or other consideration of any kind. The request for a refund may be made by the learner at any time without limitations before, during, or after course participation.

## Fetal Alcohol Spectrum Disorder

### Course Outline

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## Overview

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible life-long implications. The identifiable conditions associated with prenatal alcohol exposure under the FASD umbrella are Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (PFAS), Alcohol-Related Neurodevelopmental Disorder (ARND) and Alcohol-Related Birth Defects (ARBD).

An FAS diagnosis indicates impairments in three categories, 1) growth deficiency, 2) central nervous system dysfunction (developmental disability or brain damage) and, 3) a characteristic set of facial dysmorphology or malformation.

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. When signs of brain damage appear following fetal alcohol exposure in the absence of other indications of FAS, the condition is termed "alcohol-related neurodevelopmental disorder" (ARND).

## Epidemiology

### Prevalence of FASDs

The center for Disease Control (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. These rates are comparable to or greater than other common developmental disabilities such as Down syndrome or spina bifida. Of the approximately 4 million infants born each year, an estimated 1,000 to 6,000 will be born with FAS. 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. This translates to about 40,000 alcohol-affected births per year in the United States.

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. Among children in foster care, the prevalence rate for FAS is 15 cases per 1,000 children. Finally, among individuals in the juvenile justice system, more than 200 per 1,000 (20%) were found to have FAS or a related disorder.

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. 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.

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. 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.

### **Maternal Alcohol Use**

Drinking Among Women Age 15 to 44 in the United States:

- 1 in 2 reports using alcohol use in the past month.
- Approximately 1 in 4 reports binge drinking (defined as 4 or more drinks for a woman, 5 or more for a man, on one occasion).
- About 1 in 20 reports heavy alcohol use (defined as binge drinking on at least 5 days in the last month).

Drinking Among Pregnant Women in the United States:

- 3.5% of pregnant women engage in high-risk drinking (7 or more drinks per week, or 5 or more drinks on any one occasion).
- 1 in 9 pregnant women binge drinks in the first 3 months of her pregnancy.
- 1 in 30 pregnant women drinks at levels that increase the risk of FASD.
- 20% of pregnant women report drinking in the first trimester, 7% in the second trimester, and 5% in the third trimester.
- Those who are unmarried and over 30 have the highest rates of alcohol use in pregnancy.
- The rate of past month binge drinking among pregnant women age 15 to 17 (8.8%) is more than twice that of pregnant women age 26 to 44 (3.8%).
- Among women of childbearing age entering substance abuse treatment, 4% were pregnant.
- Eighteen percent of pregnant women entering treatment say that alcohol is their primary substance of abuse.

## **Associated Costs**

### **Financial Cost**

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. The estimated lifetime cost for one individual with FAS more than \$2 million. This is an average for all people with FAS. Those with severe problems have much higher costs.

### **Societal Cost**

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. 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. 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. 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.

## **Risk Factors**

Any pregnant woman is at risk of having a child with an FASD if she drinks alcohol during her pregnancy. Alcohol can harm an embryo or fetus at any time, even before a woman knows she is pregnant. Women who drink and don't use contraception and women who have an alcohol dependence or other alcohol use disorder are at an increased risk for having a child with an FASD. Women who have previously given birth to a child with an FASD and continue to drink are also at an increased risk of having additional children who are affected. Poor general health and lack of proper

nutrition may also increase the harmful effects of prenatal alcohol exposure as could genetic factors that have yet been fully established.

**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 reported that, within the United States, the incidence of FAS at sites characterized by low socioeconomic status were about 10 times higher than at sites with predominant middle or high socioeconomic status.

**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. Nevertheless, epidemiological studies show that younger women have higher rates of heavy drinking and alcohol-related problems than do older women. Women ages 21 to 30 have the highest rates of intoxication, problem drinking, heavy episodic drinking, and alcohol dependency symptoms, and have a low number of abstainers compared with older age groups.

**Age of First Drink** - Women who began drinking before age 14 are at greater risk of developing alcohol dependence. Additionally, women who started drinking earlier in life are least likely to stop drinking during pregnancy and are more resistant to intervention. One of the best predictors of continued drinking during pregnancy is length of drinking history.

**Number of children and previous child with FAS** - 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, the rate increases to 771 in 1,000 live births for the younger sibling of a child with FAS.

**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.

**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.

**Depression** - In reviews of the literature on women and alcohol use, depression is consistently documented as part of a complex etiology of drinking problems. Studies have shown that women who are experiencing symptoms of depression consume more drinks per occasion and are less able to reduce their alcohol consumption, thus impeding the effectiveness of intervention attempts.

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.

**Heavy alcohol use by partner/family member/peers** - 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.

Family members can influence drinking behavior actively, by explicitly encouraging or discouraging alcohol use, or passively, by providing models of drinking behavior. This is particularly true for adolescent women. Social influences from friends and family members, particularly mothers, are highly predictive of teen alcohol use.

Peers' substance abuse is one of the strongest predictors of alcohol use during pregnancy, as is family alcohol use. Women of all ages whose social environments encourage alcohol use will be less amenable to reducing their drinking during pregnancy.

**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. Several factors might explain why binge drinking is harmful to fetal brain development. 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.

### **Fetal Alcohol Metabolism**

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.

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.

The embryo has limited ability to metabolize alcohol, mostly because the 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.

### **Causal Mechanisms**

The mechanisms that underlie alcohol-induced fetal brain damage have been studied in experimental animals and in nerve cells (i.e., neurons) grown in culture. Within the fetus, embryonic cells destined to become brain neurons grow in number, move to their ultimate locations, and mature into a wide variety of functionally distinct neuronal cell types, eventually forming connections with other brain cells in a predetermined pattern. Alcohol metabolism is associated with increased susceptibility to cell damage caused by potentially harmful substances called free radicals. Free radical damage can kill sensitive populations of brain cells at critical times of development in the first trimester of pregnancy. Other animal experiments suggest that the third trimester may also represent a particularly sensitive period for brain cell damage associated with FAS. Alcohol or its metabolic breakdown products can also interfere with brain development by altering the production or function of natural regulatory substances that help promote the orderly growth and differentiation of neurons.

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:

- 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.

## Neuropathology

The behavioral and cognitive impairments associated with FASD reflect underlying structural or functional changes in the brain. Techniques for viewing the living brain, such as magnetic resonance imaging (MRI), reveal reduced overall brain size in persons with FASD and disproportionate reductions in the size of specific brain structures.

One such area is the deep-brain structure called the basal ganglia. Damage to the basal ganglia impairs spatial memory and set shifting in animals and various cognitive processes in humans. Another common finding is reduced size of the cerebellum, a structure involved in balance, gait, coordination, and cognition. Finally, prenatal alcohol exposure is the major cause of impaired development or complete absence of the corpus callosum, a band of nerve fibers that forms the major communication link between the right and left halves of the brain. Approximately 7 percent of children with FAS may lack a corpus callosum, an incidence rate 20 times higher than that in the general population.

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.

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, pencephaly, 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. Similar malformations were observed in animal models subjected to fetal alcohol exposure.

More recent investigations into the morphological changes that occur as a result of fetal alcohol exposure indicate the presence of significant changes in the corpus callosum, the major connecting pathway between the two halves of the cerebral cortex.

Fetal alcohol exposure might cause predictable alterations in the corpus callosum structure that are detectable by magnetic resonance imaging (MRI) or sonography.

### **Gestational Sensitivity**

Development of the nervous system begins in about the third week of gestation and continues throughout gestation. An estimated 95–100 billion neurons are found in the human cortex, making the rate of generation nearly 250,000 new neurons formed each minute of the 9-month gestational period in the cortex alone. 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. 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.

### **Neuromorphological Effects**

Alcohol has the following neuromorphological effects on the developing fetus:

- 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.

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- 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.

### **Effects on Neurotransmitter Receptors**

Effects of alcohol exposure during the development of 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.

### **Effects on Signal Transduction**

Specific transduction events within cells in response to stimulation are affected by fetal alcohol exposure. 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.

## **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

### **Cellular Response to Alcohol Exposure**

Substantial research has examined the cellular responses and molecular mechanisms affected by fetal alcohol exposure. These investigations and descriptions have been

associated with one or more of the following processes during neural development.

### **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.

### **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.

### **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”.

### **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.

### **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.

### **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.

## **Diagnosis**

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 four of the following:

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

### **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 vermilion (University of Washington Lip-Philtrum Guide – ranking of 4 or 5)
- Small palpebral fissures (at or below 10<sup>th</sup> 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.

**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. 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 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.

**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.

## **Growth Problems**

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

Confirmed prenatal or postnatal height, weight, or both at or below the 10<sup>th</sup> percentile documented at any one point in time (adjusted for age, sex, gestational 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.

## **Central Nervous System Abnormalities**

CNS abnormalities can be structural, neurological, or functional. Documentation of

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problems in one or more of these areas is necessary for the FAS diagnosis.

### **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:

*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

*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)

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.

### **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.

### **Screening**

Most children diagnosed with fetal alcohol-related problems are not identified before they reach school age, when they are referred for a learning disability or an attention deficit disorder. Screening for early identification of FASD has several important benefits including early intervention and improved educational and functional



outcomes for infants, toddlers and young children. Early screening increases the number of young children identified and this allows them early access into intervention programs. Early intervention increases the amount of time these very young children can be served in the critical developmental periods of life. An additional and often unappreciated benefit for many infants and toddlers is that early treatment decreases the duration of some aspects of FASD, which may, in turn, decrease the severity and frequency of associated problems. For example, speech and language delays (commonly seen in children with FASD) are often associated with the development of difficulties relating to peers and are strongly associated with reading problems at school age. Early intervention for an infant or toddler in this case could result in positive changes in behavior, decreased temper tantrums and less difficulty with reading in later development.

Selective or indicated screening and program or population-based screening are two common strategies used in screening for FASD. Only trained health care providers and specialists are qualified to screen and diagnose young children with FASD.

### **Selective or Indicated Screening**

All infants, toddlers and young children whose mothers have current alcohol use disorders or a recent history of alcohol use should be screened. These very young children are at increased risk for FASD. This strategy identifies three groups of children typically screened.

- 1.) Children whose mothers have received substance abuse treatment or who have legal problems suggestive of alcohol abuse. Although some mothers use alcohol with other substances including methamphetamine, crack and intravenous drugs, all infants and toddlers of substance abusing mothers should be screened regardless of type of substance abuse.
- 2.) Children who are in foster care or relative care because of a maternal history of substance abuse and children whose mothers are in jail or prison due to a drug-related charge would be screened. Although others are caring for these very young children, they are likely to be at risk for having FASD due to maternal substance use and abuse.
- 3.) Infants, toddlers and young children with siblings who have FASD should be screened. Young children in this population are very likely to have FASD since there is up to a 75 percent rate of this disorder co-occurring in siblings who have brothers or sisters with FASD.

### **Program or Population-Based Screening**

A second type of screening program is a systematic program-based screening for FASD. Using this method, all children who enter a program would be screened by a trained health care specialist and either ruled-out for FASD or referred for further

screening, diagnosis and early intervention. This is much more effective for identification of infants, toddlers and young children who are at increased risk for FASD.

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 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.

## **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.

## **Cognitive and Behavioral Impairments**

The broad range of cognitive and behavioral disabilities associated with prenatal alcohol exposure was attributed by many researchers to a generalized impairment of mental functioning. However, recent studies on FAS and ARND reveal that specific neurobehavioral functions are consistently impaired, whereas others are spared. Thus, the outlook for persons diagnosed with FAS or ARND should not be considered hopeless. Some specific neurobehavioral impairments associated with prenatal alcohol exposure are discussed below.

## **Verbal Learning**

Children prenatally exposed to alcohol exhibit a variety of problems with language and

memory. For example, children with FAS ages 5 to 16 learn fewer words compared with children of comparable mental age who do not have FAS. However, both groups demonstrate equal ability to recall information learned previously. This indicates that FAS-related verbal learning problems occur during the initial stages of memory formation (i.e., encoding). Once encoded, verbal information can be retained and recalled, subject to normal rates of forgetting. Clinically, this pattern helps distinguish FAS from Down's syndrome, in which learning and recall are equally impaired.

### **Visual-Spatial Learning**

Children of mothers who drank heavily during pregnancy often perform poorly on tasks that involve learning spatial relationships among objects. Children with and without FAS are equal in their ability to recall common, small household and schoolroom objects (e.g., a paper clip or spoon) placed within sight on a table and then removed. However, children with FAS have greater difficulty subsequently restoring the objects to their original positions on the table.

### **Attention**

Attention problems are considered a hallmark of prenatal alcohol exposure. Consequently, FAS is often incorrectly diagnosed as attention deficit hyperactivity disorder (ADHD) and treated inappropriately. Children with ADHD typically exhibit difficulty focusing and sustaining attention over time. In contrast, children exposed to alcohol prenatally are able to focus and maintain attention, but display difficulty in shifting attention from one task to another.

### **Reaction Time**

Individual differences in intelligence are based in part on how quickly the brain processes information. Prenatal alcohol exposure is associated with slower, less efficient information processing in school-age children.

### **Executive Functions**

Important deficits in FAS involve executive functions (i.e., activities that require abstract thinking, such as planning and organizing). For example, problems with set shifting are common, as noted earlier. Children prenatally exposed to alcohol respond poorly when asked to switch from naming animals to naming types of furniture, and then back to naming animals. They also have difficulty abandoning demonstrably ineffective strategies when approaching problem-solving tasks, a type of behavioral inflexibility referred to as perseveration. Perseveration and impaired set shifting are consistent with distractibility and impulsivity, factors that at least theoretically might contribute to attention and learning problems.

### **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. 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).

### Early Intervention

Although research has demonstrated that early diagnosis and intervention with infants, toddlers and young children with FASD may improve long term outcomes, the diagnosis is associated with specific risks across the life span. Pediatric specialists and other qualified professionals often have the following concerns and questions when assessing very young children with this disorder:

- Is this infant at high risk for abuse and neglect?
- Does the child have birth defects (heart defects are especially common)?
- Is this child in foster care or at high risk for out of home placement?
- Does the child have increased susceptibility to infectious illness?
- Is the child at risk for inadequate health care and follow-up of known health problems?

FASD is a serious and long-term problem and many young children with this disorder require annual evaluations. At each evaluation, parents, caregivers, teachers and health care providers should be provided with information on the management of age-appropriate behavior and development of specific issues they will encounter with their infant or toddler. This information sharing among team members will help prevent some of the problems and minimize the severity of many others. In order to effectively manage FASD, parents, caregivers, teachers, and health care providers are encouraged to ask questions, anticipate developmental events, share information and learn the signs for early identification in young children.

The following three examples could be problems with infants and toddlers who do not have FASD but are often more pronounced in young children diagnosed with the disorder.

**1. Sleep problems.** Few problems are more difficult for parents than infants who have sleep disturbance. Infants and toddlers impacted by FASD often have difficulty maintaining a regular sleep schedule. Lack of sleep disrupts parents' ability to care for infants and increases irritability, frustration and feelings of helplessness, all raising the risk for child abuse. Parents can be supported in establishing sleep schedules for infants and toddlers and managing frequent nighttime awakening for very young children. An important step in getting infants and toddlers to sleep through the night is setting a regular four or five step bedtime routine (It's almost bedtime, time to brush your teeth, get your PJs on, let's do our bedtime story – you pick the book and time to go sleep). It's important to get ready for sleep with quiet activities. The use of a

consistent schedule, having a nap routine and responding with consistency to infants or young children who have difficulty sleeping will often be the first steps toward self-regulation.

**2. Regulation of Emotions.** Caregivers expect to see a wide range of emotions in healthy functioning infants and toddlers. Several useful strategies can help parents manage these behaviors. The first is for parents to be sure they have control over their own emotions. Infants and toddlers with FASD frequently have episodes of extreme emotional outbursts for which typical calming strategies are not quickly effective. For caregivers, the inability to help calm or soothe an infant or toddler can be distressing and often frustrating. Strategies for infants and toddlers with FASD such as holding, rocking or playing soft music may help soothe these children after a period of time. Bouncing, loud noise, or becoming upset are not helpful parenting strategies.

Temper tantrums are common in older toddlers and preschoolers with FASD. Health care providers can ask a few simple questions to help them determine how to respond to a young child having a temper tantrum. For example, do temper tantrums often follow some event or do they seem to be occurring at random? Can the young child be taught how to respond to the event or similar events? Parents are encouraged to sit quietly nearby without responding while the temper tantrum is occurring, as many young children will not continue if they do not have an audience. Temper tantrums are also strongly associated with speech and language delays as young children with FASD often become easily frustrated by their own inability to communicate clearly. Early identification and entry into speech and language therapy can be very helpful in managing temper tantrums in young children with FASD.

**3.) Social Skill Deficiencies.** In young children with FASD, social skills are often impaired. In older toddlers and preschoolers, these deficiencies are often seen as challenging behaviors and include aggression, poor turn taking, difficulty with cooperative play, and problems in age-appropriate social interaction. A common response is to give the young child a consequence for displaying challenging behavior with the goal of modifying the behavior. Sometimes adults assume that the young child has the necessary social skills to function in settings with other peers and siblings and that they are “choosing” not to use these skills. However, many young children with FASD have difficulty understanding how to respond to peers and adult caregivers in social situations that, for them, are confusing.

It is more helpful to teach the young child appropriate responses to each social situation by anticipating problems before they occur. Parents, teachers and providers can use these “teachable moments” to elicit the desired response and encourage the young child to use the new skills in home and classroom settings. This approach-often called anticipatory guidance-utilizes positive rewards, skill rehearsal and catching the young child “being good.” Focusing on the desired behaviors in young children with FASD encourages them to continue working on their learned skills. This also encourages parents, caregivers and providers to “expect” these young children to display the desired behaviors more frequently. For the adults in the young child’s life,

the goal is to help them understand these behavioral issues as skill deficiencies rather than simply willful misbehavior.

### **Considerations for a Referral for an FAS Diagnostic Evaluation**

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 maternal 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 vermilion, 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

### **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. Individuals affected by prenatal alcohol exposure often present with challenges in multiple domains of

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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.

### **Contextual Considerations**

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. 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 estimated to be 10–15 times higher than in the general population. 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. It has been estimated that two thirds of affected children are not raised in their biological homes, 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 no 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. For example, parents of children affected by prenatal alcohol exposure report high levels of stress; this stress is believed to be caused in part by impairments in the child's adaptive, behavioral, and executive functioning. 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. 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.

### **Developmental Considerations**

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". 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.

Parents 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 and executive functioning 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).

### **Goals of the Evaluation**

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

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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". The evaluation team should anticipate the possibilities of these issues when working with families of individuals with prenatal alcohol exposure.

## **Components of an Evaluation**

### **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.

### **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.

### **Clinical interview with parents/caregivers**

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, 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.

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.

### **Presenting Concerns and Reason for Assessment**

Although initial information about presenting concerns and the family's reason for 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

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.

### **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. 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.

### **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, depression, or having a partner who is using alcohol.

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.

### **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, 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.

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.

### **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, skeletal defects, and dental problems. 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. Hearing problems are also not uncommon in alcohol-affected individuals.

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,

### **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. 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.

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.

### **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. 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.

- 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.

### **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.

### **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.

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.

### **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?
- 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 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.

### **Strengths and resources**

In evaluating individuals with FASDs, 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 be extremely useful when designing a treatment plan for the individual, as these strengths can be capitalized on during intervention.

It is also helpful to identify 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.

## 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, 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.

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

- *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)?
- *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?
- *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)?
- *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:

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

## **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. It has been established 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. 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. 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.

## **Secondary Conditions**

Fetal alcohol spectrum disorders (FASDs) often lead to other disorders, called "secondary conditions." Secondary conditions are problems that a person is not born with, but might get as a result of having an FASD. These conditions can be improved or prevented with appropriate treatments for children and adults with FASDs and their families. Following are some of the secondary conditions that have been found to be associated with FASD:

Innovative Educational Services

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### **Mental Health Problems**

There is an increased risk for cognitive disorders (e.g., problems with memory), mental illness, or psychological problems among people with FASDs.

The most frequently diagnosed disorders are:

- Attention problems, including attention-deficit/hyperactivity disorder (ADHD)
- Conduct disorder (aggression toward others and serious violations of rules, laws, and social norms)
- Alcohol or drug dependence
- Depression

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

### **Disrupted School Experience**

Children with FASDs are at a higher risk for being suspended, expelled, or dropping 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 FASDs remain in school but have negative experiences because of their behavioral challenges. Disrupted school is experienced by 14% of children and 61% of adolescents with FASDs. Approximately 53% of adolescents with FASDs have been suspended from school, 29% have been expelled, and 25% drop out.

### **Trouble with the Law**

Teenagers and adults with FASDs are at a higher risk for having interactions with police, authorities, or the judicial system. Difficulty controlling anger and frustration, combined with problems understanding the motives of others, result in many people with FASDs being involved in violent or explosive situations. People with FASDs can be very easy to persuade and manipulate, which can lead to their taking part in illegal acts without being aware of it. Trouble with the law is reported overall for 14% of children and 60% of adolescents and adults with FASDs.

### **Inappropriate Sexual Behavior**

People with FASDs are at higher risk for showing inappropriate sexual behavior, such as inappropriate advances and inappropriate touching. If the person with an FASD is also a victim of violence, the risk of participating in sexually inappropriate behavior increases. Inappropriate sexual behaviors increase slightly with age from 39% in children to 48% in adolescents and 52% in adults with FASDs.

### **Alcohol and Drug Problems**

More than a third of adults with FASDs experience problems with alcohol or drugs, with more than half of that requiring inpatient treatment.

### **Dependent Living and Problems with Employment Over 21 Years**

Adults with FASDs generally have difficulty sustaining employment or living independently in their communities.



## Concerns Across a Lifespan

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.

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 non-routine sequence or manner (i.e., different or scattered development). It is important to note that these two concepts are not necessarily mutually exclusive in any particular child, but on the whole characterize the general types of developmental disabilities.

In regard to delayed development, young children or infants who are not meeting milestones on time are said to have developmental delay. 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. This latter path of development often results in “peaks and valleys” of strengths and weaknesses, which very much describes individuals with FASDs. 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. 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.

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.

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). 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.

## **Infants**

Prenatal alcohol exposure has been associated with increased negative affect and higher rates of insecure attachment behavior, poorer habituation and orientation, problems with state and autonomic regulation, increased post-stress cortisol levels, and less mature motor behavior and increased level of activity. Feeding difficulties are not uncommon, and infants with prenatal alcohol exposure might present in medical settings with failure to thrive. Infants with FASDs often have sensory and regulatory problems. 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. Additionally, infants with FASDs often have poor immune function and experience multiple bouts of otitis media and upper respiratory infections. 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

## **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. 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.

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. 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).

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.

### **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. 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.

Visual-spatial abilities and math skills are also areas of weakness for children with FASDs. In fact, weaknesses and deficits in these domains are one of the earliest and most robust findings for this population. These two domains are likely developmentally related, and problems in one affect the other. 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. Further, deficits in visual perception, visual memory, visual-motor integration

(i.e., drawing and writing), and spatial memory have been reported by many investigators. Early visual-spatial deficits and weaknesses have been related to poor performance on arithmetic achievement tests.

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.

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, and many end up in special education. Children with prenatal alcohol exposure also exhibit high rates of externalizing behavior and attention problems, 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. 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.

## **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 driver's license, or just "fitting in." All of these issues create low self-esteem leading to a difficult adulthood.

Adolescents with FASDs are at greater risk than adolescents without FASDs of developing substance abuse problems, 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.

Parents of adolescents with FASDs might begin to worry about victimization, high-risk behavior, and delinquency, and seemingly with good reason. Researchers have documented 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. Adolescents with FAS have trouble getting along with peers, and often engage in inappropriate sexual behavior.

School problems are also likely to continue to be a major concern. Studies have found that approximately 53% of adolescents with FAS 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 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.

## **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.

For many affected adults, basic tasks of daily living, such as maintaining steady employment, managing money, and obtaining medical care present major challenges. High rates of psychiatric disorders among adults diagnosed with FAS have been documented, including alcohol or drug dependence, depression, psychotic disorders, and various personality disorders. It is estimated that 60% of adults with FAS have had problems with the law, and approximately half have 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.

### **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. 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).

## **Keys to Treatment Success**

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.

Working with a child with an FASD involves many joys and many challenges. Although each child is unique, the following list of tips can be helpful.

- 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 aids, music, and hands-on experience to assist with the learning process.
- Use positive reinforcement often (praise, incentives).
- Supervise: friends, visits, routines.
- Repeat, repeat, repeat.

## **The Feedback Process**

### **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.

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.

### **Structure and format of feedback to the family.**

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. The family should receive a meaningful explanation 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 obtained 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.

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.

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.

### **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. 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. 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.

### **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 and school professionals. 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.

## **Educational Interventions**

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 for children with FASD are guaranteed under the Individuals with Disabilities Education Act (IDEA), which was reauthorized under the Individuals with Disabilities Education Improvement Act.

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. 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. 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.

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.

## **Alternative Approaches**

As with any disability, injury, or medical condition, many untested therapies become known and are advocated by informal networks. Health care professionals 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

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biofeedback; auditory training; 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.

## Supplemental Information

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## Fetal Alcohol Spectrum Disorder

### Post-Test

1. Which demographic group has the highest rate of maternal alcohol use during pregnancy? (p. 4)
  - A. Unmarried teens
  - B. Married teens
  - C. Unmarried over 30 years old
  - D. Married 20-30 years old
2. Which of the following is NOT an identified maternal risk factor for FASD? (p. 6)
  - A. Lower socioeconomic status
  - B. Hypothyroidism
  - C. Genetic predisposition
  - D. Depression
3. Alcohol passes easily via diffusion from maternal blood into the fetal blood. (p. 8) A. True B. False
4. Prenatal alcohol exposure to the developing fetal brain may cause \_\_\_\_\_. (p. 9)
  - A. Damage to the hypothalamus
  - B. Reduction to the size of the cerebrum
  - C. Impaired development of the corpus callosum
  - D. Hypertrophy of the amygdala
5. Nervous system development begins in about the eighth week of gestation. (p. 10) A. True B. False
6. Alcohol is passed to infants postnatally via breast milk. (p. 11) A. True B. False
7. The four requirements for establishing a diagnosis of FAS are \_\_\_\_\_. (p. 13)
  - A. facial dysmorphism, growth deficits, CNS abnormalities, and maternal alcohol exposure
  - B. facial dysmorphism, growth deficits, alpha-1 ketones in cerebral spinal fluid, and maternal alcohol exposure
  - C. growth deficits, CNS abnormalities, fetal blood alcohol level of .08, and alpha-1 ketones in cerebral spinal fluid
  - D. facial dysmorphism, CNS abnormalities, elevated alpha-1 ketones in cerebral spinal fluid, and maternal alcohol exposure
8. Facial dysmorphism is established by examining the lip philtrum and the palpebral fissures. (p. 13-14)  
A. True B. False
9. FAS related CNS abnormalities can be structural, neurological, or functional. (p. 14-15) A, True B. False
10. Which of the following is NOT a common FAS related cognitive or behavioral impairment (p. 18-19)
  - A. Problems with language and memory
  - B. Visual-spatial learning issues
  - C. ADHD
  - D. Executive function deficits
11. A child should be referred for full FAS evaluation when there is confirmed significant maternal prenatal alcohol use. (p. 22) A. True B. False

## Fetal Alcohol Spectrum Disorder

12. The goal of a multidisciplinary collaborative evaluation is \_\_\_\_\_. (p. 26)
  - A. Assess the individual's current level of functioning—both his or her areas of difficulty and his or her strengths and resources.
  - B. Assess the interactions and relationships between the individual and his or her family and other important figures in the individual's life.
  - C. Provide recommendations for treatment and intervention that will optimize the functioning of both the individual and the important figures in his or her environment.
  - D. All of the above
13. Which of the following is NOT typically part of a comprehensive FASD evaluation? (p. 27-39)
  - A. Comprehensive history
  - B. Functional MRI and EEG
  - C. Behavioral observations
  - D. Standardized testing
14. Which of the following statements regarding FASD secondary conditions is FALSE? (p. 39-40)
  - A. Approximately 25% of adolescents with FASD drop out of school.
  - B. Teenagers and adults with FASDs are at a higher risk for having interactions with police, authorities, or the judicial system.
  - C. People with FASDs are at higher risk for showing inappropriate sexual behavior, such as inappropriate advances and inappropriate touching.
  - D. More than half of the adults with FASDs experience problems with alcohol or drugs.
15. Overall, \_\_\_\_\_ are considered areas of strength of individuals with FASDs. (p. 41)
  - A. executive functions
  - B. basic language skills
  - C. visual spatial skills
  - D. math related skills
16. Children with FASDs often display difficulties understanding social boundaries, reading social cues, and relating to peers. (p. 44) A. True B. False
17. All the cognitive, behavioral, and functioning problems associated with FASDs typically decrease during adolescence. (p. 44) A. True B. False
18. The keys to working successfully with children with FASDs include structure, consistency, variety, brevity, and persistence. (p. 47) A. True B. False
19. What are the primary goals of providing feedback to the family? (p. 47-48)
  - A. Report the results of the evaluation and recommend interventions.
  - B. Educate the family about prenatal alcohol exposure and FASD.
  - C. Provide emotional support to the family.
  - D. All of the above
20. Early intervention programs for children with FASD are guaranteed under the \_\_\_\_\_. (p. 51)
  - A. Individuals with Disabilities Education Act (IDEA)
  - B. Federal Healthy Child Initiative (FHCI)
  - C. United States Rehabilitative Care Program (USRCP)
  - D. Intervention and Education Program (IEP)

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