

# Fetal Alcohol Syndrome:

## Guidelines for Referral and Diagnosis



National Center on Birth Defects and Developmental Disabilities  
Centers for Disease Control and Prevention  
Department of Health and Human Services

in coordination with

National Task Force on  
Fetal Alcohol Syndrome and Fetal Alcohol Effect



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American Academy of Pediatrics  
American College of Obstetricians and Gynecologists  
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National Organization on Fetal Alcohol Syndrome

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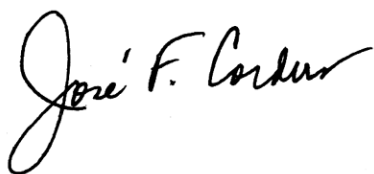
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## Foreword

The National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention, in collaboration with the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, is pleased to present *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis*. This document represents the deliberations of clinicians, researchers, parents, and representatives of governmental and non-governmental organizations, whose main goals were to increase the identification of individuals with fetal alcohol syndrome (FAS) using uniform criteria, and to improve the delivery of appropriate services to those individuals and their families. These new guidelines will help achieve those goals by educating medical and allied health professionals about FAS.

In 2003, we, in the FAS research and practice communities, celebrated the 30th anniversary of the first reports describing fetal alcohol syndrome. Since that time we have learned a great deal about this preventable condition. We now recognize that FAS represents the tip of the iceberg and that there is a continuum of outcomes associated with prenatal exposure to alcohol. These guidelines were undertaken, in part, as an effort to facilitate further identification, understanding, and study of all conditions resulting from prenatal exposure to alcohol. They build on previous work and incorporate important scientific and clinical knowledge that has been obtained in recent years. CDC is pleased to provide continuing support for the expansion and refinement of scientific descriptions for FAS and other disorders related to prenatal exposure to alcohol through its ongoing work with the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect and the federal Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS).

Preventing all adverse outcomes associated with prenatal alcohol exposure remains a primary goal of CDC, as well as the entire U.S. Department of Health and Human Services. CDC is committed to working with other federal agencies, organizations in the private sector, relevant partners, and the public to achieve this goal. Similarly, CDC is committed to enhanced early identification of individuals with FAS and related disorders to ensure their access to appropriate services. These latest guidelines for referral and diagnosis are an important step towards that goal. Together we will ensure all persons with FAS and related disorders develop optimally and reach their full potential.



José F. Cordero, M.D., M.P.H.  
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# Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis

## EXECUTIVE SUMMARY

As part of the fiscal year 2002 appropriations funding legislation, the U.S. Congress mandated that the Centers for Disease Control and Prevention (CDC), acting through the National Center on Birth Defects and Developmental Disabilities (NCBDDD) Fetal Alcohol Syndrome (FAS) Prevention Team and in coordination with the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (NTFFAS/FAE), other federally funded FAS programs, and appropriate non-governmental organizations, would:

- Develop guidelines for the diagnosis of FAS and other negative birth outcomes resulting from prenatal exposure to alcohol,
- Incorporate these guidelines into curricula for medical and allied health students and practitioners, and seek to have them fully recognized by professional organizations and accrediting boards, and
- Disseminate curricula to and provide training for medical and allied health students and practitioners regarding these guidelines.

Through the coordinated efforts of CDC, the NTFFAS/FAE, and a scientific working group (SWG) of experts in FAS research, diagnosis, and treatment, the following diagnostic criteria were developed over a 2-year period:

### Facial dysmorphism

Based on racial norms, individual exhibits all three characteristic facial features:

- Smooth philtrum (University of Washington Lip-Philtrum Guide rank 4 or 5)
- Thin vermilion border (University of Washington Lip-Philtrum Guide rank 4 or 5)
- Small palpebral fissures (at or below 10th percentile )

### Growth problems

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

### Central Nervous System Abnormalities

#### I. Structural

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



## II. Neurological

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

## III. Functional

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

1. Global cognitive or intellectual deficits representing multiple domains of deficit (or significant developmental delay in younger children) with performance below the 3rd percentile (2 standard deviations below the mean for standardized testing)

or

2. Functional deficits below the 16th percentile (1 standard deviation below the mean for standardized testing) in at least three of the following domains:
  - a) cognitive or developmental deficits or discrepancies
  - b) executive functioning deficits
  - c) motor functioning delays
  - d) problems with attention or hyperactivity
  - e) social skills
  - f) other, such as sensory problems, pragmatic language problems, memory deficits, etc.

## Maternal Alcohol Exposure

- I. Confirmed prenatal alcohol exposure
- II. Unknown prenatal alcohol exposure

## Criteria for FAS Diagnosis

Requires all three of the following findings:

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

A primary goal of these guidelines is to provide standard diagnostic criteria for FAS so that consistency in the diagnosis can be established for clinicians, scientists, and service providers. The guidelines are based on state-of-the-art scientific research, clinical expertise, and family input regarding the physical and neuropsychological features of FAS. The SWG sought to harmonize these guidelines with other diagnostic systems currently in use in this country and others (e.g., Canada). The SWG strove to provide a balance between conservative and overly inclusive diagnostic systems. Differential diagnosis from other genetic, teratological, and behavioral disorders was emphasized.

In addition to diagnostic guidelines, guidance about medical, educational, social, and family services appropriate for individuals with FAS and their families are reviewed. Services that are applicable to all individuals with FAS and their families, as well as age-specific services, are included. Such services focus on increasing parent and professional knowledge of FAS, characteristics of the disorder,



der, differences between FAS and other disorders, and appropriate techniques for parenting or educating affected individuals.

Prevention of FAS and related disorders is of tremendous public health importance. A large amount of research in recent years has enabled researchers and service providers to develop programs that are effective and targeted to specific populations for reducing the risk of an alcohol-exposed pregnancy, which prevents FAS. This research is reviewed herein and recommendations for identifying and intervening with women at risk for an alcohol-exposed pregnancy are provided.

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



# Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis

Substantial empirical and clinical scientific evidence has shown that prenatal exposure to alcohol causes damage to the developing fetus. Such exposure is commonly cited as the leading preventable cause of birth defects and developmental disabilities (1-3). Children\* exposed to alcohol during fetal development can suffer multiple effects. While the number and severity of negative effects can range from subtle to serious, the negative consequences are lifelong. The effects of prenatal exposure to alcohol and basic diagnostic features of fetal alcohol syndrome (FAS) were first described in the United States (U.S.) medical literature 30 years ago (4-8). In 1981, the U.S. Surgeon General issued a public health advisory warning that alcohol use during pregnancy could cause birth defects (9). Further, mandated labeling of alcohol products was established in 1989 (10). Despite the known adverse effects of prenatal exposure to alcohol, many children who experience these adverse effects do not receive proper diagnosis due to the absence of current diagnostic guidelines. These current guidelines, which were federally mandated of the Centers for Disease Control and Prevention (CDC) in the U.S. Department of Health and Human Services (DHHS) 2002 Appropriations Bill, seek to update and refine diagnostic and referral criteria in light of the scientific and clinical advances in the understanding of this disorder during the past 30 years.

These guidelines are organized into several sections. Background information and a history of the development of these guidelines are presented. Next, revised and refined diagnostic and referral criteria for FAS are described, including the empirical and clinical evidence that support each criterion. Comparison of these guidelines with other diagnostic methods currently in use is provided. Because diagnosis is not the endpoint for most clinicians who see children with FAS, a discussion of the essential services for affected individuals is included. Likewise, prevention of FAS by reducing the number of alcohol-exposed pregnancies is inherent in dealing with the disorder. Therefore, a discussion focused on identifying and intervening with women at risk for an alcohol-exposed pregnancy is provided. Finally, a discussion of future needs and efforts related to FAS and other prenatal alcohol-related disorders conclude this report.

## BACKGROUND

*Prevalence.* Studies by CDC have reported FAS prevalence rates from 0.2 to 1.5 cases per 1,000 births across various populations (11-14). Other studies reflecting a variety of ascertainment methodologies have produced estimates ranging from 0.5 to 2.0 cases per 1,000 live births (15-16). Such rates are comparable with or above other common developmental disabilities such as Down syndrome or Spina Bifida (17). Using the CDC FAS estimates, among the approximately 4 million infants born each year, an estimated 1,000 to 6,000 will be born with FAS. Studies of particularly vulnerable populations yield prevalence estimates that far exceed those of other common disabilities. Disadvantaged groups, Native Americans, and other minorities have been documented to have

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\* Although referral and diagnosis for FAS can be made throughout the lifespan, the majority of individuals are referred and diagnosed in childhood. Thus, the terms “child” or “children” as used in these guidelines are not intended to preclude referral, assessment, and diagnosis of older individuals.

rates as high as three to five FAS affected children per 1,000 children (18-20). Available data also suggest that poverty is strongly associated with women's alcohol use before and during pregnancy, leading to an excess of children with FAS in impoverished groups (21-22).

The magnitude of the problem is even greater when the risk of FAS is considered by looking at the rate of alcohol-exposed pregnancies. In 1999, over half of all U.S. women of childbearing age reported alcohol consumption in the past month (23). The large majority of these women drank only occasionally, but 15% could have been classified as moderate or heavy drinkers (24-25). During that same period, 13% of women reported consuming five or more drinks on one occasion (binge drinking) in the past month (26). Given that nearly half of all U.S. pregnancies are unintended, and that millions of fertile women are sexually active while not using adequate contraception, an estimated 2% of women could be at risk for an alcohol-exposed pregnancy annually (27). More recently, higher rates have been found among subgroups of women, such as those treated for alcohol and drug problems, and women who have been incarcerated (28). Alcohol-related risk factors include drinking during pregnancy, pattern of alcohol use, alcohol dependence, use of multiple substances, having had a previous alcohol-exposed pregnancy, and having a partner or family member who drinks heavily (29-31). Women who receive little or no prenatal care, are unemployed, are socially transient, have lost children to foster or adoptive care because of neglect, abuse, or abandonment are more likely to have high alcohol use patterns that could affect a pregnancy (22,32). National survey data indicate that, while the percentage of women who abstain from alcohol use during pregnancy has increased slightly in recent years, 13% of women continue to use alcohol during pregnancy (26). Among pregnant women, approximately three percent report binge drinking (i.e., five or more drinks on any one occasion) or frequent drinking (i.e., seven or more drinks per week or five or more drinks on any one occasion) (1,33-34). Clearly, current prevalence rates of affected individuals and alcohol-exposed pregnancies indicate that the magnitude of the problem of FAS is a significant public health concern. However, because of the challenges of establishing accurate and timely prevalence information, the magnitude could be even greater than current data indicate.

*Challenges in determining accurate prevalence.* Despite the progress made over the past several decades to accurately establish and monitor the prevalence of FAS, the full magnitude of the problem is still not known. Primary care providers and others who care for children do not routinely or consistently identify individuals with FAS, which hinders efforts to account for these children in routine birth defects and developmental disabilities monitoring programs. Studies using multiple data sources (e.g., birth certificates, clinical charts, and medical records) show wide variations in identification of FAS cases depending on the population being surveyed (15,34). Four major factors lead to widespread failure to recognize FAS in primary pediatric care settings resulting in underestimates of the prevalence and impact of FAS (36-38):

- **No specific and uniformly accepted diagnostic criteria have been available.** The four broad areas of clinical features that constitute the diagnosis of FAS have remained essentially the same since first described in 1973: selected facial malformations, growth retardation, Central Nervous System (CNS) abnormalities, and maternal alcohol consumption during pregnancy. These four areas were reaffirmed in a 1996 report by the Institute of Medicine (IOM; 39-40). However, these broad areas of diagnostic criteria are not sufficiently specific to ensure diagnostic accuracy, consistency, and reliability. For example, clinicians do not have guidance about how many facial features must be present or the timing and severity of growth retardation needed to constitute

FAS diagnostic criteria. Thus, health providers are hampered in their efforts to screen and identify children with FAS.

- **FAS diagnosis is based on clinical examination of features, but not all children with FAS look or act the same.** Because each of the symptoms has a broad range of differential diagnoses, it is easy for a clinician to miss or misdiagnose FAS. Previous guidelines, including those included in the 1996 IOM report, did not account for children of different racial and ethnic groups or individuals of different ages. In addition, symptoms such as growth impairment, cognitive impairment, and learning disabilities can have a range of causes. Some of these causes or disorders have higher visibility and recognition than FAS, leading to misdiagnosis (or at least failure to include FAS in the total diagnosis). For instance, physicians are aware of the high prevalence of Attention Deficit, Hyperactivity Disorders (ADHD), but might not link attention problems to FAS. Without clear diagnostic criteria and instruction on their use, providers will continue to under-identify and under-diagnose FAS.
- **Lack of knowledge and misconceptions among primary care providers.** Many professionals believe that FAS can only occur if the mother is an alcoholic. Few know about the full range or progressive nature of the neurobehavioral symptoms that result from prenatal exposure to alcohol. Some incorrectly believe that FAS only occurs among low-income families or in Native American or other racial and ethnic minority groups (21). Better information on the impact of FAS among all populations and dissemination of race or ethnic variations in the diagnostic criteria can help clinicians understand the risk of prenatal alcohol exposure across populations. Knowledge about subpopulation variations in facial characteristics as well as growth curves for infants by gestational age also are important considerations (41).
- **Lack of diagnostic criteria to distinguish FAS from other alcohol-related conditions.** Creating and using diagnostic guidelines for FAS is a starting point for better defining the continuum of conditions related to prenatal alcohol exposure (40). FAS is a severe outcome of prenatal alcohol exposure. Other outcomes also occur and can result in major deficits. Terms such as Fetal Alcohol Effect (FAE), Alcohol-related Birth Defect (ARBD), and Alcohol-Related Neurodevelopmental Disorder (ARND) have been used to describe a spectrum of conditions related to prenatal alcohol exposure.

These four challenges indicate that what is urgently needed to advance the field of FAS diagnosis are current diagnostic guidelines based on empirical evidence as well as clinical experience. Such guidelines should be based on up-to-date scientific evidence and current clinical practices. Further, such guidelines would allow public health and service professionals to better determine the impact of FAS, and deliver needed services to affected children.

*Congressional mandate.* As part of the fiscal year 2002 appropriations funding legislation, Congress mandated that CDC, acting through the National Center on Birth Defects and Developmental Disabilities (NCBDDD) and in coordination with the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (NTFFAS/FAE), other federally funded FAS programs, and appropriate nongovernmental organizations, would:

- Develop guidelines for the diagnosis of FAS and other negative birth outcomes resulting from prenatal exposure to alcohol;

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

*Limit in scope.* The mandate to CDC indicates that, in addition to guidelines for FAS, guidelines should be developed for other negative birth outcomes resulting from prenatal exposure to alcohol. However, it was subsequently determined through discussions with all interested stakeholders that the best course was to first develop guidelines for the full FAS diagnosis (see following). Then, in subsequent efforts, these guidelines could be expanded or refined to include other alcohol-related disorders. This approach was determined to provide the most timely and scientifically grounded guidelines at this time. However, this decision does not curtail ongoing efforts to define conditions beyond FAS or develop diagnostic guidelines for those conditions.

*Note on terminology.* Many terms are used to describe the continuum of effects that result from prenatal exposure to alcohol, including: Fetal Alcohol Effect, Alcohol-related Birth Defects, and Alcohol-Related Neurodevelopmental Disorder. A more recent term that has been introduced is Fetal Alcohol Spectrum Disorders (FASD). In April 2004, several federal agencies [(National Institutes of Health (NIH), CDC, & Substance Abuse and Mental Health Services Administration (SAMHSA)] along with experts in the field were convened at a summit sponsored by the National Organization on FAS (NOFAS) to develop a consensus definition of FASD. The resulting definition, adopted in these guidelines, is:

*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 lifelong implications. The term FASD is not intended for use as a clinical diagnosis.*

## APPROACH AND METHODS FOR DEVELOPMENT OF GUIDELINES

To meet its Congressional mandate, CDC convened an internal working group, led by staff from the FAS Prevention Team of NCBDDD, to conduct preplanning meetings to determine the best methods for development of all aspects of the guidelines: (a) general framework for referral and diagnosis, (b) development of guidelines for physical features (dysmorphia and growth) as well as exposure, and (c) development of guidance to clinicians concerning potential CNS abnormalities. Each of these aspects involved review of the literature, as well as discussions with consultants, clinicians, researchers, and parents of affected children. A description of general and specific methods of development of each aspect follows.

*General review of literature.* CDC staff identified various reports and documents to be used as the scientific basis for diagnostic guidelines. The science base for this work included, but was not limited to:

- Published scientific, peer-reviewed, literature on physical and neurodevelopmental effects of prenatal exposure to alcohol;
- The report of the IOM Committee to study FAS (40);
- Results from the work of the NTFFAS/FAE (42) ;
- Criteria from standard, widely used dysmorphology and neurodevelopmental textbooks or guides (40,43-44);
- Research on measuring the FAS facial phenotype (45-47);
- Reports on systems that operationally interpret the 1996 IOM criteria(48-50);
- Experience in developing a surveillance case definition for the Fetal Alcohol Syndrome Surveillance Network (FASSNET) (51);
- Ongoing state surveillance and research data, particularly work of Alaska (19,35,52), Colorado (53), New Jersey, Nevada, Washington, and the Four State FAS Consortium (consisting of North Dakota, Montana, Minnesota, and South Dakota);
- The American Academy of Pediatrics (AAP) August 2000 statements and recommendations on FAS and other effects related to maternal alcohol use (54); Position of the American Academy of Family Physicians, which refers to the AAP statement; and
- Canadian National Committee's efforts concerning standardization of guidelines for screening, diagnosis, and surveillance of FAS.

*Framework.* Before developing the specifics of the diagnostic and referral guidelines, CDC staff determined that it would be helpful to conceptualize the entire diagnostic and referral process encountered by affected individuals and their families. Such a framework also would assist professionals in understanding their specific role in the referral and diagnostic process, as well as guide them with next steps for each case. The framework was reviewed by health care policy consultants as well as members of the NTFFAS/FAE. Revisions were made based on their suggestions. This framework is presented in detail later in these guidelines.

*Creation of the Scientific Working Group.* The first step in development of the guidelines was to convene an internal CDC working group. The group consisted of members of the NCBDDD FAS prevention team, geneticists, developmental pediatricians, epidemiologists, and psychologists, as well as other allied health professionals. This internal working group developed a list of potential external experts who could be convened to develop the actual guidelines. The large external panel of experts was designated as a scientific advisory panel. From this panel, a subset of experts formed a Scientific Working Group (SWG) that delineated the specifics of the diagnostic criteria.

The external SWG convened by CDC included researchers, clinicians in general and specialty medicine, representatives from academic centers and state health agencies, as well as consumer representatives from the National Organization on FAS (NOFAS) and The Arc of the United States. The scientific advisory panel met in Atlanta, Georgia, on July 12, 2002, to begin deliberations on the proposed guidelines. At that meeting, four subgroups were created: FAS Referral and Diagnosis; ARND issues; Essential Services for Children with FAS/ARND; and Identifying and Intervening with Women at Risk for an Alcohol-Exposed Pregnancy. The subgroups met and began deliberations related to the guidelines in their respective topic areas.

A subsequent meeting of the SWG occurred on September 20, 2002, in conjunction with an NTF-FAS/FAE meeting, also in Atlanta. This offered the opportunity for information sharing and feedback on progress made thus far from a range of stakeholders represented on the NTFFAS/FAE



(e.g., parents, providers, and researchers). The FAS Referral and Diagnostic subgroup and the Essential Services subgroup met to further deliberate on their recommendations. The recommendations from these two subgroups were then presented to the NTFFAS/FAE for review and input. The component of the criteria for FAS screening and diagnosis that presented the most difficulty to the FAS Referral and Diagnosis subgroup was the central nervous system (CNS)/neurobehavioral component. This group felt that members of the ARND subgroup were most qualified to develop that particular component of the criteria.

The ARND subgroup drew important information from a poll of the experts that was conducted to identify the CNS/neurobehavioral domains most affected by prenatal alcohol exposure (further description follows). Results of this poll were incorporated into the FAS Referral and Diagnosis Guidelines within the CNS/neurobehavioral component. The third meeting of the FAS Referral and Diagnosis subgroup was teleconferenced on March 11, 2003, and draft guidelines were reviewed and revised. At that time and based on review of the available scientific evidence concerning diagnosis of ARND, the scope of the guidelines was limited to FAS, with future efforts to be devoted to other prenatal alcohol-related disorders. This revised version of the diagnostic criteria was presented to and approved by the NTFFAS/FAE on March 13, 2003 with recommendations. Consensus among members of the external SWG and the NTFFAS/FAE was used to finalize each criterion of the guidelines for dysmorphology, growth, and prenatal exposure to alcohol. At the December 8 and 9, 2003, meeting of the NTFFAS/FAE, further discussions were held regarding the CNS/neurobehavioral criteria and subsequent revisions were made. Finalization of the FAS criteria was reached during a teleconference of the NTFFAS/FAE on May 13, 2004.

*Highlights of deliberations of SWG: Physical criteria.* The SWG concluded that a strict definition of FAS should be established first, not including diagnostic terms such as fetal alcohol effect (FAE), alcohol-related neurodevelopment disorder (ARND), and alcohol-related birth defect (ARBD) at this time because of insufficient scientific evidence on which to base diagnostic criteria for these related conditions. The SWG urged that CDC diagnostic guidelines for FAS use objective, quantitative measures to improve accuracy and reproducibility and apply specific case definitions guided by evidence-based knowledge and new technologies. The SWG also recommended use of racial and ethnic norms for facial features, head circumference (occipitofrontal circumference, OFC), and other key features when available.

During its deliberations, the SWG acknowledged the need to keep recommendations for the diagnosis of FAS relevant to practitioners working in clinical settings. Also, the SWG acknowledged differences between screening, diagnosis, surveillance, and research activities and the separate definitional needs of each of these activities. Effective tools and practical strategies for primary care settings were considered. The SWG encouraged CDC to call for action and collaboration among obstetricians, pediatricians, family practice physicians, and others providing primary care and screening services to children. The SWG also discussed the need for more data regarding the range of essential services for children who are diagnosed positive for FAS and stressed the importance of a multidisciplinary plan for care that links to the child's community healthcare provider or medical home.

*Central nervous system abnormality criteria.* Because the scientific evidence and professional consensus on CNS criteria are not yet at the level of specificity equal to that available for physical features, a different approach was used in developing CNS criteria. Further, it was decided that rather than

creating strict criteria for specific CNS domains and level of severity needed, more general guidelines should be described. Such general guidelines should assist the clinician in identifying areas of deficit most likely to be found with individuals who have FAS, as well as individuals with FAS who have less common types of deficits. This approach was considered optimal because a number of structures of the brain are affected versus a single, isolated structure. This generalized nature of damage from prenatal alcohol exposure can result in a wide array of neurodevelopmental outcomes.

To develop such neurodevelopmental guidelines for referral and diagnosis for FAS, the ARND/CNS subgroup polled clinicians and researchers who have extensive knowledge and experience with individuals who have FAS or other related diagnoses. These experts were individuals who specialize in neurobehavioral issues, have extensive research and clinical experience making the FAS/ARND diagnosis, and have contact with families and children with FAS. They were queried to find out what behavioral domains they encountered most frequently or were most essential for making an FAS/ARND diagnosis. Twenty-two clinicians were contacted and their responses were synthesized. The clinicians were asked to identify five areas of deficit they considered most important for diagnosis of FAS or related disorders. In addition, the clinicians were also asked to identify three to five specific behaviors that could be used as examples of each of the five areas of deficit.

The resulting guideline of neurodevelopmental features associated with FAS are presented as being as inclusive as possible, while understanding that certain areas of neurodevelopmental functions are more vulnerable to prenatal exposure to alcohol. Each domain is presented so as to include exemplars from direct observation or parent report that can be documented through standardized testing.

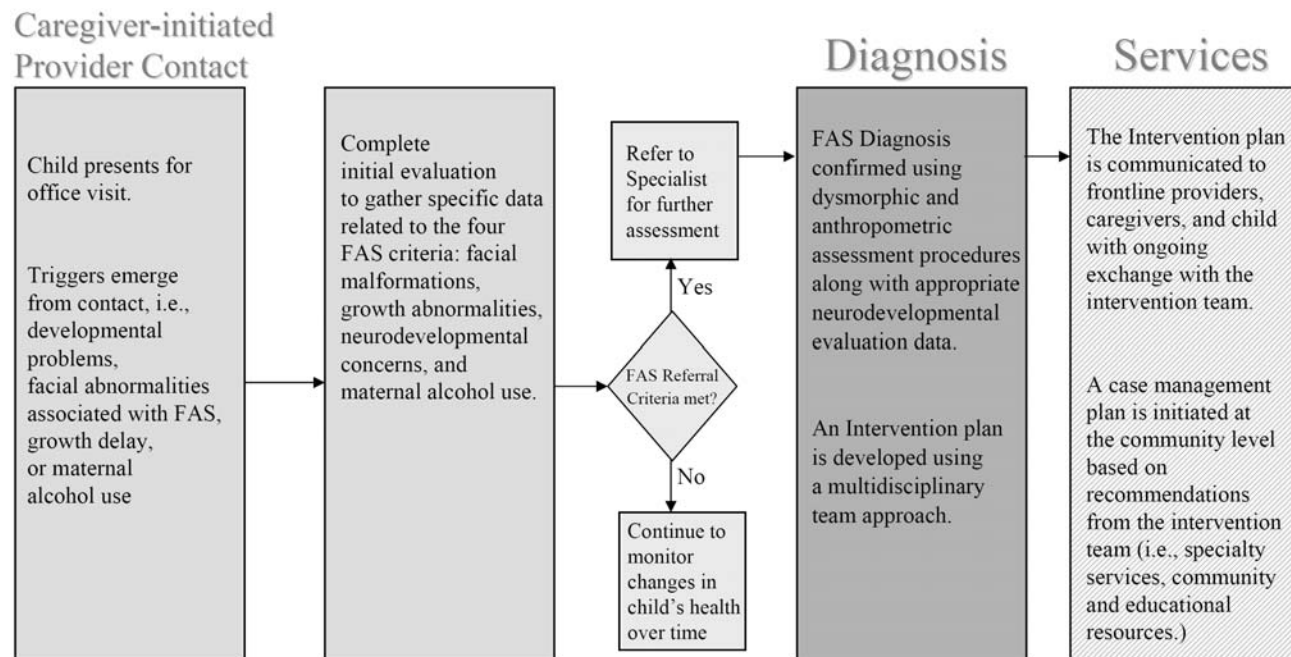
Medical diagnostic criteria are generally evaluated in two ways: (1) the criteria must be reliable and; (2) the criteria must be as valid as possible. The criteria that appear in these diagnostic guidelines meet both of these requirements. In developing these diagnostic guidelines, the SWG also considered the feasibility of applying the criteria in primary care practice and related settings where children are seen.

## **DIAGNOSTIC AND REFERRAL FRAMEWORK**

The framework in Figure I was developed to help guide the discussions of the SWG as they deliberated on the guidelines for referral and diagnosis of FAS. The framework was developed to provide an overview of the entire identification, referral, diagnosis, and treatment process. This overview guided the SWG in identifying key points that needed to be addressed to develop specific guidelines. The framework reflects CDC's recommendation that developmental screening be implemented to improve children's health and help them reach their full potential. A discussion of the major points of the framework follows.

*Initial identification.* Initial recognition that a child or older individual has a potential problem can come from many sources. Often, parents notice differences between a child and his or her siblings. School systems, including Head Start and daycare staff, interact with a large number of children and often recognize when someone is having difficulty. Social service professionals, such as WIC clinic staff, social workers, and foster care agencies frequently recognize children and individuals having difficulty and needing evaluation. And finally, healthcare providers (particularly pediatricians) often are the first to screen for and detect problems; or obstetricians, who might be aware of

**FIGURE 1. Framework for FAS Diagnosis and Services**



a maternal substance abuse problem, might refer a newborn. Recognition of many of the problems associated with FAS is exactly the type of condition the “well child” visits to the doctor’s office are meant to identify. It is assumed that triggers, such as facial abnormalities, growth delay, developmental problems, or maternal alcohol use, will emerge from the contact. Recognition of a potential problem should lead the provider, regardless of specific profession, to facilitate getting the person and his or her family to the appropriate next step.

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

*Diagnosis.* At this stage, the child would be presented to a multidisciplinary team who would engage in a more thorough assessment of the child using FAS diagnostic procedures to evaluate dysmorphia and growth parameters, as well as obtain appropriate neurodevelopmental evaluation data. Once a diagnosis is made, an intervention plan would be developed using a multidisciplinary team approach. A variety of specialists could contribute to the multidisciplinary team, including dysmorphologists, developmental pediatricians, psychiatrists, psychologists, social workers, and educational specialists. Other clinicians, such as pediatricians and family practitioners, also might make the FAS diagnosis, with appropriate training in use of these guidelines. In many rural and less populated regions, these clinicians must make the diagnosis for many types of birth defects and developmental

disabilities. Many of these evaluation services are available within the community setting, for example school systems could provide neurocognitive assessments.

## DIAGNOSTIC CRITERIA

*Dysmorphia.* Human congenital malformations are referred to as dysmorphic features or dysmorphia (55). Dysmorphia occurs when normal morphogenesis is interrupted, creating a particular feature which is shaped, sized, or positioned outside the normal range of development. Alcohol is a teratogen that results in dysmorphia through interference with nerve cell development and functioning, alterations in the ability of cells to grow and survive, increased formation of cell-damaging free radicals, altered pathways of biochemical signals within cells, and altered expression of certain genes and genetic information. In short, alcohol has been shown to interfere with fetal nerve cell development and function in a variety of ways (56-57).

In first describing the dysmorphic features of FAS, Jones and colleagues focused on short palpebral fissure, maxillary hypoplasia (with prognathism), and the presence of epicanthal folds that were observed for a majority of the children described. However, other features also were noted for some patients, including altered palmar flexional crease patterns (i.e., hockeystick crease), cardiac anomalies, joint disability, overlapping fingers, ear anomalies, hemangiomas, ptosis, hypoplastic nails, and pectus deformities (4,5). Over the next 30 years, additional features described included: microcephaly, short nose, smooth philtrum with thin vermilion border, cleft lip, micrognathia, protruding auricles, short or webbed neck, vertebra and rib anomalies, short metacarpal bones, meningocele, hydrocephalus, and hypoplastic labia majora (43).

Despite the heterogeneity of expression for dysmorphic features related to prenatal exposure to alcohol, core facial dysmorphia have emerged through human and animal studies. Experimental studies with a mouse model and primates indicate that the facial dysmorphia observed for individuals with FAS are the result of disturbances of cellular migration during organogenesis along the midline of the face (58). Using anthropomorphic measurements of all facial features, clinical researchers have confirmed the midline feature abnormalities (59). Studies of clinic-referred samples also support these features as discriminant for FAS (60-61). Based on these scientific findings and the extensive clinical experience of the SWG, the following facial dysmorphic features were determined to meet the dysmorphia criteria essential for FAS (based on racial norms):

- Smooth philtrum (measured as 4 or 5 on Lip-Philtrum Guide\*)
- Thin vermilion border (measured as 4 or 5 on Lip-Philtrum Guide) (i.e., upper lip)
- Small palpebral fissures (measured as  $\leq$ 10th percentile according to age and racial norms)

The individual must exhibit all three characteristic facial features; however, additional features also can be present. For example, maxillary hypoplasia is often noted for individuals with FAS as well as those associated features described previously. Cross-sectional and longitudinal studies indicate that many features can change with age or development. After puberty, the characteristic facial features associated with FAS can become more difficult to detect (62). However, recent findings indicate that these three key features remain for the majority of individuals with FAS (47,50).

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\* University of Washington Lip-Philtrum Guide (49-50).



Use of these three cardinal features (smooth philtrum, thin vermilion border, and small palpebral fissures) to assess whether an individual's dysmorphia is consistent with FAS, is compatible with the IOM report and other diagnostic systems currently in use. Specific criteria were chosen by the SWG to maximize inclusiveness of potential cases on this diagnostic parameter and, therefore, might differ somewhat from other systems currently in use. For example, the 1999 version of University of Washington 4-digit code system uses the same philtrum and vermilion border criteria (as noted by reference to its Lip-Philtrum Guide), but uses a cutoff of the 3rd percentile (2 or more standard deviations below the norm) for palpebral fissures, which is a more conservative cutoff (50). This more conservative approach results in fewer individuals meeting the dysmorphia criteria for an FAS diagnosis but also reduces potential false positives for the diagnosis. Other ways to assess dysmorphia for the FAS diagnosis include checklists or weighted checklists (63-65). Of those checklists reviewed by the SWG, all designated the philtrum, vermilion border, and palpebral fissures as the cardinal facial features of FAS (either by higher weighting or explicit notation). However, because of the cumulative nature of some such lists, an individual who has several of the associated features but not the cardinal features could still be given the FAS diagnosis. Thus, the checklists tend to be more inclusive than the current guidelines, with greater potential for false-positive diagnoses. Review of available diagnostic systems seems to indicate that the dysmorphic criteria agreed upon by the SWG provide a balance between conservative and overly inclusive diagnostic systems.

*Differential diagnosis of dysmorphia.* Individual dysmorphic features are not unique to any particular syndrome. Even rare defects or certain clusters of dysmorphic features can appear in a variety of syndromes. Therefore, a process of differential diagnosis is essential in making an accurate FAS diagnosis. Following, in Table 1 is a list of syndromes with dysmorphic features that overlap with the primary features of the FAS diagnosis (43). As can be seen from Table 1, none of the syndromes with single overlapping features (except for Toluene embryopathy) have the full constellation of small palpebral fissures, thin vermilion border, and smooth philtrum. However, there are some syndromes in which the constellation of features (primary, occasional features, or both) give a "gestalt" that is similar to the "gestalt" of FAS. These syndromes should be considered in particular when completing the differential diagnosis. Table 2 lists these syndromes, along with the overlapping and differentiating features.

*Growth problems.* Growth retardation, variably defined, has been documented consistently in individuals with FAS. However, these observations used a variety of parameters (e.g., height, weight, and head circumference), severity levels (below 25th percentile, below 10th percentile, or below 3rd or 2nd percentile), and timing of growth problems (current, birth or present at any point during life). The SWG reviewed available literature, clinical expertise, and practical issues to arrive at benchmarks for each of these three aspects of growth abnormalities.

The primary parameters of growth that need to be impaired to meet the growth retardation criteria of FAS are height, weight, head circumference, or a combination thereof. Anecdotally, a small number of children with FAS have been found to have disproportionate height in relation to weight. However, because multiple organic factors can lead to growth deficiencies (e.g., brain structure abnormalities leading to poor skeletal growth or disruption of endocrine function leading to poor weight gain), and because most children with FAS are symmetrical for height and weight (66), it was determined that deficiencies in *either* height or weight, but not height for weight, should be included as growth parameters that might be affected by FAS. Thus, children with growth retarda-

**Table 1. Differential diagnosis of individual features associated with FAS**

Feature	Syndromes
Smooth philtrum	Cornelia de Lange syndrome Floating-Harbor syndrome Geleophysic dysplasia Opitz syndrome Toluene embryopathy
Thin Vermillion border	Miller-Dieker (Lissencephaly) syndrome Fetal Valproate syndrome Geleophysic dysplasia Cornelia de Lange syndrome Toluene embryopathy
Small palpebral fissures	Campomelic dysplasia DiGeorge sequence Dubowitz syndrome Duplication 10q sequence Duplication 15q sequence FG syndrome Maternal phenylketonuria (PKU) fetal effects Oculodentodigital syndrome Opitz syndrome Trisomy 18 syndrome Williams syndrome Velocardiofacial syndrome Toluene embryopathy

Note: Features that discriminate these disorders from FAS can be found in Jones, 1997.

tion in height or weight would meet the growth retardation criteria for the FAS diagnosis. Consistent with poor brain development, it was determined that head circumference should be included as a CNS parameter rather than a growth parameter (67-68).

Severity of growth retardation has been defined for each parameter as at or below the 10th percentile or at or below the 3rd percentile by a majority of FAS studies. The primary issue for severity is inclusion or exclusion of children for the FAS diagnosis. Use of the 10th percentile would result in more false-positive FAS diagnoses; while use of the 3rd percentile would result in a greater number of false-negatives. For public health reasons of capturing the largest number of children who might need services, the 10th percentile was chosen by the SWG. As noted previously in the dysmorphia section, use of the 10th percentile strikes a balance among criteria used in other diagnostic systems. Again, the 1999 edition of the University of Washington 4-digit code takes a conservative approach, using the 3rd percentile as the cutoff. Checklist systems often do not specify a particular level of growth retardation and some do not specify which growth parameters should be considered (i.e., height, weight, or height relative to weight). This lack of specificity could lead to inconsistency in diagnostic method, which in turn, could lead to inconsistent application of the FAS diagnosis.

**Table 2. Differential diagnosis of syndromes similar to FAS**

Syndrome	Overlapping Features	Differentiating Features
Aarskog syndrome	Small nose with anteverted nares, broad philtrum, maxillary hypoplasia, and wide-spaced eyes	Rounded face, down-slant to palpebral fissures, widow's peak, crease below lower lip, incomplete out folding of upper helices, and dental eruption problems.
Williams syndrome	Short palpebral fissures, anteverted nares, long philtrum, depressed nasal bridge, and epicanthal folds	Wide mouth with full lips, stellate pattern of the iris, periorbital fullness, and connective tissue disorders.
Noonan's syndrome	Low nasal bridge, wide-spaced eyes, and epicanthal folds	Down-slant to palpebral fissures, keratoconus, wide mouth, and protruding upper lip
Dubowitz syndrome	Short palpebral fissures, wide spaced eyes, and epicanthal folds	Shallow supraorbital ridge with nasal bridge near the level of the forehead, and broad nasal tip
Brachmann-DeLange syndrome	Long philtrum, thin vermilion border, anteverted nares, and depressed nasal bridge	Single, bushy eyebrow extending across forehead, long eyelashes, downturned mouth, high arched palate, and short limbs (yielding short stature)
Toluene embryopathy	Short palpebral fissures, mid-face hypoplasia, smooth philtrum, and thin vermilion border	Micrognathia, large anterior fontanel, down-turned mouth corners, hair patterning abnormalities, bifrontal narrowing, and ear abnormalities
Fetal hydantoin syndrome (Fetal dilantin syndrome)	Wide-spaced eyes and depressed nasal bridge	Short nose with bowed upper lip
Fetal valproate syndrome	Epicanthal folds, anteverted nares, long philtrum with thin vermilion border, and wide-spaced eyes	High forehead, infraorbital crease or groove, and small mouth
Maternal PKU fetal effects	Epicanthal folds, short palpebral fissures, long underdeveloped philtrum, and thin vermilion border	Small upturned nose, round facies, and prominent glabella



The current guidelines provide consistent growth parameters that should be assessed, as well as a more inclusive level of the 10th percentile.

The primary issue that emerged in the discussion of timing of growth retardation was whether growth retardation needs to be present at the time of the diagnosis, or whether it could have occurred previously and been resolved. This is particularly important when including prenatal growth retardation or early growth problems due to failure to thrive. Because a great number of treatments exist for growth problems (e.g. feeding tubes or hormone therapy), the SWG adopted the criteria that any history of growth retardation, including prenatal growth deficiencies, should be allowed within the diagnostic criteria (61).

Thus, the growth retardation criteria adopted by the SWG are: confirmed prenatal or postnatal height, weight, or both at or below the 10th percentile documented at any one point in time (adjusted for age, sex, gestational age, and race or ethnicity). The committee noted that 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.

*Differential diagnosis of growth problems.* Growth retardation and growth deficiencies occur in children, adolescents, and adults for a great many reasons. Some of the most obvious reasons have to do with insufficient nutrition. This could be a particular problem for infants with poor sucking responses who experience failure to thrive. In addition, several genetic disorders result in specific growth deficiencies (e.g., dwarfism). Prenatal growth retardation can be due to a variety of factors, including maternal smoking or other behaviors leading to hypoxia, poor maternal nutrition, or genetic disorders. Both environmental and genetic bases for growth retardation should be considered for differential diagnosis when considering the FAS diagnosis.

*Central nervous system abnormalities (CNS).* More than 2,000 scientific papers regarding the teratogenic effects of alcohol exposure for CNS have been published over the past 30 years (69-71). Studies of the impact of fetal exposure to alcohol show a range of short- and long-term cognitive and behavioral outcomes resulting from these CNS abnormalities. Complicating detection of these abnormalities is that FAS neurobehavioral presentation changes across the lifespan (4,61,72-79). Despite this developmental process, CNS deficits generally persist throughout the lifespan (80). Longitudinal studies have found that many adults affected by FAS have complex mental health disorders, are affected by the consequences of neurobehavioral deficits, and are unable to sustain independent living (81). Prenatal exposure to alcohol can result in an array of structural, functional, neurological problems, or a combination of these, as well as abnormalities of the CNS (40). To meet the FAS diagnostic criteria for CNS abnormality, structural, neurological, or functional deficits, or a combination thereof, must be documented. Note that it is also possible for an individual to present with more than one CNS structural, neurological, functional deficit or abnormality. Guidelines for each type of CNS abnormality follow.

## **I. Structural**

1. Documented small or diminished overall head circumference (OFC at or below the 10th percentile) adjusted for age and gender (including head circumference at birth; 4,68). For children who have overall growth deficiency (i.e., height and weight below the 10th percentile) to meet this criteria for CNS abnormality, the child's head circumference should be disproportionately small to his or her overall size (i.e., OFC at or below the 3rd percentile).

2. Clinically significant brain abnormalities observable through imaging techniques (e.g. reduction in size, or change in shape of the corpus callosum, cerebellum, or basal ganglia) as assessed by an appropriately trained professional (4,58,82-88).

Note: An individual could meet the CNS abnormality criteria for the FAS diagnosis through a structural abnormality, yet not demonstrate detectable functional deficits.

## **II. Neurological**

Documented evidence of neurological damage to the CNS. Neurological problems of CNS can include seizures not due to a postnatal insult or fever or other soft neurological signs outside normal limits (e.g., in coordination, visual motor difficulties, nystagmus, or difficulty with motor control; 89-92). As with head circumference, abnormal neurological findings can be most predictive of underlying CNS abnormality due to prenatal alcohol exposure, rather than later environmental factors, in younger children. The use of norm-referenced measures of neurological functioning is recommended.

## **III. Functional**

Assessment findings that indicate deficits, problems, or abnormalities in functional skills of the CNS. Early brain damage is usually generalized rather than specific, with increased specificity of abnormalities revealed as development progresses. The functional abilities affected by prenatal exposure to alcohol vary greatly from person to person, depending on the amount of alcohol exposure, timing of exposure, and pattern of exposure (e.g., chronic exposure versus binge episodes). Despite this inherent variation in effects, several areas of significant functional vulnerability have been observed consistently by clinicians and clinical researchers with particular damage to corresponding structures reported (e.g., corpus callosum, cerebellum, or basal ganglia). Variability in exposure impact results in variability of structural, neurological, or functional deficits, or a combination thereof in affected individuals.

For functional deficits, it is generally accepted that multiple locations in the brain (and corresponding functional capability) are affected by prenatal exposure to alcohol. To address this issue, functional deficits that fulfill the CNS abnormality criteria can be met in two ways:

**(1) Global cognitive deficit (e.g., decreased IQ)  
or significant developmental delay in children too young for an IQ assessment;**

**OR**

**(2) Deficits in THREE or more specific functional domains**

These two ways of meeting the criteria for a functional CNS abnormality were adopted because of the composite nature of cognitive/intellectual and developmental measures (93-94). Decreased performance on a standardized measure of cognition/intelligence or development assumes deficits in multiple domains. In the absence of such a measure, several specific domains need to be assessed individually to determine that multiple functional domains have been affected. The specific domains most often cited as areas of deficit or concern for individuals with FAS are described below, although other domains and abilities can be affected and this list is not exhaustive. It should

be noted that for each of the following specific domains described, other agents and environmental factors can produce deficits or outcomes similar to prenatal alcohol exposure, making care differential diagnosis essential. Finally, these descriptions are intended to be suggestive and examples of likely and possible problems a clinician might encounter then need to assess using psychometric instruments. The exemplars are not intended to be exhaustive, or to present a necessary list of behaviors to be used as a checklist without reliable and valid assessment.

- a) **Cognitive deficits or significant developmental discrepancies.** It is important to note that global deficits or delays can leave the child scoring in the normal range of development, but below what would be expected for his or her environment and background (61,95-99). In addition to formal testing (either through records or current testing), behaviors that may be observed (or reported) in the clinical setting that suggest cognitive deficits or developmental delays that should be assessed by standardized testing include but are not limited to **specific learning disabilities (especially math and/or visual-spatial deficits); uneven profile of cognitive skills; poor academic achievement; discrepancy between verbal and nonverbal skills; and slowed movements or reaction to people and stimuli (e.g., poor information processing).** (75,100-103)
- b) **Executive functioning deficits.** Executive functioning (EF) is defined as the ability to maintain an appropriate problem solving set for attainment of a future goal and that this ability includes the more specific skills of inhibition, planning, and mental representation (104). Behaviors that can be observed (or reported) in the clinical setting that might indicate an EF deficit that should be assessed by standardized testing include, but are not limited to **poor organization, planning, or strategy use; concrete thinking; lack of inhibition; difficulty grasping cause and effect; inability to delay gratification; difficulty following multistep directions; difficulty changing strategies or thinking of things in a different way (i.e., perseveration); poor judgment; and inability to apply knowledge to new situations.** (105-108)
- c) **Motor functioning delays or deficits.** Both gross motor and fine motor skills can be impaired for individuals with FAS (109-111). Visual-motor/visual-spatial coordination is a particularly vulnerable area of functioning (99,112-113). Behaviors that can be seen (or reported) in the clinical setting that indicate motor problems that should be assessed by standardized testing include, but are not limited to **delayed motor milestones; difficulty with writing or drawing; clumsiness; balance problems; tremors; and poor dexterity. For infants, a poor suck is often observed.** (61,114-116)
- d) **Attention and hyperactivity problems.** Attention problems are often noted for children with FAS, with many children receiving a diagnosis of attention-deficit hyperactivity disorder (ADHD; 117). Although such a diagnosis can be applied, some research has shown that the attention problems for children with FAS do not seem to fit the classic pattern of ADHD. Individuals with FAS tend to have difficulty with the encoding of information and flexibility (shifting) aspects of attention; whereas children with ADHD typically display problems with focus and sustaining attention (118-119). Individuals with FAS also can appear to display hyperactivity because their impulsivity may lead to increased activity levels. Behaviors that may be observed (or reported) in the clinical setting that suggest attention problems related to FAS that should be assessed by standardized testing include, but are not limited to **described by adult as “busy”; inattentive; easily distracted; difficulty calming down; overly active; difficulty completing tasks; and/or trouble with transitions. Parents might report inconsistency in attention from day to day (e.g., “on”**

days and “off” days). (79,120-125)

- e) **Social skills problems.** The executive, attention, and developmental problems described previously often lead to clinically significant difficulty for people with FAS when interacting with peers and others. Because of the mental representation problems, individuals with FAS often have social perception or social communication problems that make it difficult for them to grasp the subtler aspects of human interactions (107,126-127). Consistent difficulty understanding the consequence of behavior or inappropriate behavior is frequently described for individuals with FAS (62,80). Behaviors that can be observed (or reported) in the clinical setting that indicate these types of social difficulties that should be assessed by standardized testing include, but are not limited to **lack of stranger fear; often scape-goated; naiveté and gullibility; easily taken advantage of; inappropriate choice of friends; preferring younger friends; immaturity; superficial interactions; adaptive skills significantly below cognitive potential; inappropriate sexual behaviors; difficulty understanding the perspective of others; poor social cognition; and clinically significant inappropriate initiations or interactions.** (128-130) It should be noted that standardized assessment of social problems can be quite difficult. Social functioning is a multifaceted domain that can require several areas of assessment.
- f) **Other potential domains that can be affected.** In addition to these five most often cited problem areas, deficits and problems to be assessed by standardized testing can present in several other areas, including **sensory problems (e.g., tactile defensiveness and oral sensitivity); pragmatic language problems (e.g., difficulty reading facial expression; poor ability to understand the perspectives of others); memory deficits (e.g., forgetting well-learned material, and needing many trials to remember); and difficulty responding appropriately to common parenting practices (e.g., not understanding cause-and-effect discipline).** While abnormalities in these “other” areas have been reported for some individuals with FAS, expert consensus suggests deficits in these areas present at a lower frequency than do those in the other five specific domains (62).

THESE GUIDELINES STRONGLY RECOMMEND THAT FUNCTIONAL DOMAINS BE ASSESSED USING NORM-REFERENCED STANDARDIZED MEASURES. DOMAINS SHOULD BE ASSESSED BY APPROPRIATE PROFESSIONALS USING RELIABLE AND VALIDATED INSTRUMENTS.

*Level of functional deficit.* In these guidelines, global cognitive deficits and developmental delay, or deficits in three or more specific domains, are defined as performance substantially below that expected for an individual’s age, schooling, or circumstances. Several statistical thresholds have been suggested to operationally define performance substantially below expected levels. Previous research indicates that approximately only one-quarter of individuals diagnosed with FAS perform at the most conservative level of below the 3rd percentile (2 standard deviations below the mean) on standardized measures (95). In keeping with this finding, and to adequately capture the full spectrum of effects, the SWG adopted two levels of functional deficits that would meet the criteria for a CNS abnormality: (1) for significant global cognitive deficit performance below the 3rd percentile (i.e., 2 standard deviations below the mean); and (2) for three or more specific domains performance below the 16th percentile (i.e., 1 standard deviation below the mean) on standardized measures of individual domains. Thus, individuals scoring below the normal range on a global measure of IQ or development and individuals scoring in the below average range on standardized measures of three

specific functional domains would meet the criteria for functional CNS abnormality for diagnostic purposes.

Ideally, functional deficits should be established through appropriate standardized neuropsychological testing by a trained professional. The SWG recognized that such standardized testing might not be readily available in all diagnostic settings. Clinicians are strongly encouraged to supplement their observations by obtaining standardized testing through early intervention programs, public schools, and psychologists in private practice. The SWG emphasizes the need for psychometric testing when evaluating an individual for the FAS diagnosis, and use of clinical judgment alone could veer away from the goal of implementing standard diagnostic criteria for FAS. In addition, such testing will facilitate the development of individualized and appropriate treatment plans for diagnosed individuals. These guidelines are intended to provide information concerning the types of CNS abnormalities that might be observed, as well as the level of deficit that can be expected. In addition, they seek to support the need for quality assessments administered by trained professionals when establishing CNS abnormalities associated with the FAS diagnosis.

These guidelines for assessment of CNS abnormalities for making the FAS diagnosis is in harmony with, although not duplicative of, other diagnostic guidelines and systems. The 1999 version of the University of Washington 4-digit code and the guidelines developed by Health Canada requires performance below the 3rd percentile (2 standard deviations below the mean on standardized testing) in three separate domains in which global deficits count as one domain. Some health systems might find this approach useful in situations in which resources for standardized testing are readily available.

*Mental health problems and lifelong consequence.* Difficulty in any of the functional CNS areas described above can lead to maladaptive behavior and mental health problems with lifelong consequences. Commonly co-occurring mental health issues (excluding attention problems) reported by clinicians and cited in the scientific literature to date, include *conduct disorders, oppositional defiant disorders, anxiety disorders, adjustment disorders, sleep disorders, and depression* (81,95,131-134). Although attention problems can be classified as a mental health issue or psychiatric condition, in these guidelines they are treated as a primary deficit resulting from alcohol-related CNS damage, rather than a secondary mental health issue. There are considerable animal, human, and clinical studies that document attention deficits for many individuals with prenatal exposure to alcohol (117). In addition, decreased adaptive skills and increased problems with daily living abilities have been consistently documented, although further research is needed. Such problems include dependent living conditions, disrupted school experiences, poor employment records and encounters with law enforcement (including incarceration; 95). Although these mental health and very debilitating lifelong consequences should not be used for the purpose of diagnosis, it should be noted that they are very prevalent among individuals with FAS and are very likely to be the presenting conditions that should trigger a referral and comprehensive diagnostic evaluation.

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



drome), significantly disrupted home environments or other external factors can produce functional deficits in multiple domains that overlap with the domains that are 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). *To assist with differential diagnosis between FAS and environmental causes for CNS abnormalities it is important to obtain a complete and detailed history for the individual and his or her family.*

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 will 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 (62,135). 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.* Documentation and confirmation of prenatal alcohol exposure can be extremely challenging. For birth mothers, admission of alcohol use during pregnancy can be very stigmatizing. The situation can be further complicated if the woman is still using alcohol, especially at high consumption rates. In this situation, information about alcohol use might need to be obtained from other reliable informants, such as a relative. However, the overwhelming situation encountered in the clinical setting is when a child or adult is being evaluated for FAS and little or no information about the index pregnancy is available. This frequently occurs for children in foster and adoptive homes. In this situation, every effort should be made to obtain the necessary information, but lack of confirmation of alcohol use during pregnancy should not preclude an FAS diagnosis if all other criteria are present. This would be considered “unknown prenatal alcohol exposure”. In very rare instances, there will be confirmed absence of exposure. Documentation that the birth mother did not drink any amount of alcohol from conception through birth would indicate that the FAS diagnosis is not appropriate. This typically implies that the birth mother knew the date of conception (e.g., a planned pregnancy) and did not consume alcohol from that day forward, or she was prevented from drinking for some reason (e.g., incarceration). It must be noted that simple denials of alcohol use might or might not be credible and corroborating evidence should be obtained whenever possible. However, given the imprecise nature of exposure information, the following two qualifiers for prenatal alcohol exposure were suggested by the SWG:

- I. **Confirmed prenatal alcohol exposure** requires documentation of the alcohol consumption 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.

- II. **Unknown prenatal alcohol exposure** indicates that there is neither a confirmed presence nor a confirmed absence of exposure. Examples include: 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 exist that cannot be reliably resolved.

## CRITERIA FOR FAS DIAGNOSIS

A diagnosis of FAS requires the presence of all three of the following findings:

1. Documentation of all three facial abnormalities (smooth philtrum, thin vermilion border, and small palpebral fissures);
2. Documentation of growth deficits; and
3. Documentation of CNS abnormalities (structural, neurological or functional, or combination thereof).

It should be noted that confirmed prenatal alcohol use can strengthen the evidence for diagnosis, but is not necessary in the presence of all the previous findings. Confirmed absence of alcohol exposure would rule out the FAS diagnosis. The FAS diagnosis should be made only after ruling out other possible diagnoses associated with each criterion. A brief outline of the diagnostic criteria for FAS is presented in Table 3.

*Changes in presentation of criteria across development.* As would be expected for any congenital syndrome, presentation of the diagnostic features can change over development. With regards to facial features (small palpebral fissures, smooth philtrum, and thin vermilion border), it has generally been accepted that these features are most evident during infancy and the early preschool years. However, longitudinal data that specifically address this issue are not available currently. One also might expect growth parameters to change (and generally normalize) with development. This might especially be the case for children who receive nutritional or other interventions. Perhaps the criterion for which the most change over development is observed is CNS abnormalities. While structural abnormalities would remain consistent, neurological and functional deficits could resolve or change presentation at various stages of development. During the newborn and infancy periods, difficulty with arousal or behavior regulation might be observed. Slightly older infants could display delayed or abnormal motor skills. During late infancy approaching the preschool period, general cognitive developmental delay is generally reflected through delayed milestones, especially early language acquisition (note, however, that basic language skills of vocabulary and syntax generally are not areas of deficit for children with FAS). During the preschool period, attention problems and hyperactivity can emerge. In typically developing children, the late preschool through early school age (e.g., 4 through 7 years of age) is when many executive functioning and social perception skills are acquired. For example, simple planning or organization skills are learned, as well as understanding the physical and mental perspective of others. Preschoolers and school-aged children often do not fully acquire these skills. Throughout the school-age period, children with FAS can exhibit deficits or difficulty with any of the CNS domains listed in the diagnostic criteria. However, each child's pattern of strengths and weaknesses is likely to be very individualized. During adolescence and through adulthood, the pattern of deficits continues to be present and in addition, lifelong conse-



**Table 3: Brief Outline of Diagnostic criteria for Fetal Alcohol Syndrome**

**Facial dysmorphism**

Based on racial norms, individual exhibits all three characteristic facial features:

- Smooth philtrum (University of Washington Lip-Philtrum Guide rank 4 or 5)
- Thin vermilion border (University of Washington Lip-Philtrum Guide rank 4 or 5)
- Small palpebral fissures (at or below 10th percentile )

**Growth problems**

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

**Central Nervous System Abnormalities**

**I. Structural**

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

**II. Neurological**

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

**III. Functional**

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

1. *Global cognitive or intellectual deficits representing multiple domains of deficit (or significant developmental delay in younger children) with performance below the 3rd percentile (2 standard deviations below the mean for standardized testing)*  
*or*
2. *Functional deficits below the 16th percentile (1 standard deviation below the mean for standardized testing) in at least three of the following domains:*
  - a) cognitive or developmental deficits or discrepancies
  - b) executive functioning deficits
  - c) motor functioning delays
  - d) problems with attention or hyperactivity
  - e) social skills
  - f) other, such as sensory problems, pragmatic language problems, memory deficits, etc.

**Maternal Alcohol Exposure**

- I. Confirmed prenatal alcohol exposure
- II. Unknown prenatal alcohol exposure

**Criteria for FAS Diagnosis**

Requires all three of the following findings:

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

quences of those deficits emerge, including mental health problems, inability to achieve independent living, and criminal activity (62,95,126-137).

*Individuals who do not meet the full diagnostic criteria for FAS.* The 1996 IOM report noted that most individuals with deficits resulting from prenatal exposure to alcohol do not express all of the features necessary to meet the criteria for an FAS diagnosis. This was confirmed in the comments of researchers, clinicians, and members of the NTFFAS/FAE during the deliberations of the SWG. Consensus has not been reached by either of these groups, or the scientific and clinical community at large regarding evidenced-based diagnostic criteria for any prenatal alcohol-related condition other than FAS. However, there is grave concern that individuals who present with the same neurodevelopmental deficits as individuals diagnosed with FAS, but who do not present with the full facial features or growth deficits, are not being afforded services because they are not given a diagnosis of FAS. Ongoing funding has been provided by the National Institute on Alcohol Abuse and Alcoholism (NIAAA) to conduct research that might result in evidence-based diagnostic criteria for individuals with other conditions caused by prenatal alcohol use. Currently, CDC is using a collaborative database of neurodevelopmental data from five intervention studies to explore the nature of individuals who could be considered in the diagnostic category of ARND, as well as data from a prospective cohort study of 5-year-olds in Denmark. However, at this time, the only diagnostic category with scientific evidence to support clinical criteria is FAS. As future data and science are available, these guidelines can be refined and expanded to delineate other conditions resulting from prenatal alcohol exposure.

## CONSIDERATIONS FOR A REFERRAL FOR AN FAS DIAGNOSTIC EVALUATION

Very often the front-line providers of services (medical, educational, or social) are faced with making the decision of whether or not to refer a child, individual, or family for a full FAS diagnostic evaluation. The SWG recognizes that this may be a difficult decision. For biological families, there may be social stigma associated with any evaluation concerning prenatal alcohol exposure. In other families, direct information about alcohol use during pregnancy may not be available 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 was preferable to refer for full evaluation by a multidisciplinary team with experience in evaluating prenatal alcohol exposure.

- For situations with known prenatal alcohol exposure: A child or individual should be referred for full FAS evaluation when there is confirmed significant prenatal alcohol use (i.e., 7 or more drinks per week or 3 or more drinks on multiple occasions, or both). If prenatal alcohol exposure in the high risk range is known in the absence of any other positive screening criteria, the primary healthcare provider should document this exposure and closely monitor the child's ongoing growth and development.
- 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 possibly have FAS.
  - all three facial features are present (smooth philtrum, thin vermilion border, and small palpebral fissures).

- one or more facial features are present in addition to growth deficits in height or 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.

## **SERVICES APPROPRIATE FOR AFFECTED INDIVIDUALS AND THEIR FAMILIES**

Diagnosis is never an endpoint for any individual with a developmental disability and his or her family. This is particularly true for individuals with FAS, their families, and their community. As described in the framework section, the FAS diagnosis and the diagnostic process (especially the neuropsychological assessment) are part of a continuum of care that identifies and facilitates appropriate health care, education, and community services. The learning and life skills affected by prenatal exposure vary greatly among individuals, depending on the amount of alcohol exposure and the timing and pattern of exposure, as well as each individual's current and past environment (138-139). As a result, the services needed for individuals with FAS and their families vary according to what parts of the brain have been affected, the age or level of maturation of the person, the health or functioning of the family, and the overall environment in which the person is living. Thus, service needs for any particular individual and his or her family can be quite individualistic (140).

Despite the required individualization in service needs, some general areas of service and specific services have been identified as helpful to people with FAS and their families (62). While the ideal circumstance are services and interventions that have been specifically developed for individuals with FAS and their effectiveness has been established through rigorous scientific evaluation, such programs are only now being researched and developed. Thus, most evidence for the benefit of services has been gleaned from research with other populations, clinical wisdom, and family experiences. These three sources have drawn heavily from information obtained concerning risk and protective factors that have been found through systematic research, using natural history methodology, to promote positive development or reduce the incidence of negative long-term consequences of FAS (i.e., reduce secondary conditions; 141). First, these factors will be reviewed. Then, services that are applicable to all individuals with FAS, regardless of life stage will be presented. Finally, essential services appropriate for individual life stages will be presented.

*Risk and Protective factors.* In a landmark study of secondary conditions for individuals with FAS, Dr. Ann Streissguth and her colleagues delineated not only the lifelong consequences of FAS, but also several basic factors that are protective or increase the risk of negative outcomes (95). This study identified many lifelong negative consequences of FAS, including disrupted school experiences, legal problems, incarceration, mental health problems, substance abuse problems, inappropriate sexual behavior, dependent living, and poor employment history. Importantly, these risks are not mutually exclusive. Any individual can (and most likely will) experience multiple risk factors that can have a cumulative effect (141). Moreover, these risks can be exacerbated by family and community expectations. Research has shown a relation between the number of risk factors encountered by an individual and poor outcomes. Reducing the number and severity of risk factors is an important step in providing services to individuals with FAS and their families. The disorder of FAS has often been described as a “hidden” disability because of the subtlety of the dysmorphia and good basic language skills (e.g., vocabulary and syntax) of many affected individuals. These factors lead to individuals with FAS being treated inappropriately because of caregivers’ unrealistic

developmental expectations. FAS might be either not recognized or mislabeled as stubbornness or “bad” behavior by a caregiver, or others who encounter the affected individual (e.g., teachers, extended family, and friends). Families raising children with developmental disabilities typically report considerable parental stress related to this aspect, particularly for parents of children with FAS (62).

Several factors have been identified that can potentially reduce the odds of long-term negative outcomes in children with FAS (protective factors), including a stable and nurturing home environment during the school years, early diagnosis (before 6 years of age), absence of exposure to violence, few changes in caretaking placements, and eligibility for social and educational services. Interventions and services that maximize these protective factors while reducing risk factors will provide the best benefit to anyone with FAS and improve their chances for achieving their developmental potential (95,138).

*General Needs.* Helpful interventions should include those that stabilize home placement and improve parent-child interaction (138). One method for accomplishing this goal is to increase the understanding of the disorder by parents, teachers, law enforcement personnel, and other professionals who might become involved with the affected individual. Children with FAS often need unique parenting because of their difficulty with cause and effect reasoning and other executive functioning skills. Caregiver education should highlight and explain differences in the thought processes of children with FAS from typically developing children and children with other developmental disabilities. This would enable parents to avoid potentially difficult situations (e.g., avoiding overly stimulating environments) and better manage problems when they do arise. Overall, a better functioning family that results from caregiver education promotes the stable, nurturing home that has been shown to be a positive protective factor for children with FAS (142).

Beyond the home environment, other professionals also need increased education and information concerning FAS (135). Parents can facilitate this understanding by learning to become advocates for their child. Such advocacy includes both linking families with needed community resources and making sure that the child receives maximum benefit from that service. Because the myriad of service systems is confusing and inconsistent across states, families must be educated about them at the local level. The world of social and educational services can be overwhelming, confusing, and inconsistent, and usually has a unique vocabulary that must be learned. Thus, it is important that along with a diagnosis, clinicians need to help caregivers in learning about available services, how to determine which services are appropriate for their child, and how to work productively with service providers (62).

Many prenatally exposed infants and children enter the foster or adoptive care system at an early age. A recent study estimated that the prevalence of children with FAS (or a related disorder) in the foster care system is 10 times that of the general population (143). However, while protective service agencies (PSAs) might have information about a child’s prenatal history, staff members are generally not knowledgeable about FAS, do not understand the impact of the child’s having FAS, or do not communicate the child’s FAS status to other service systems. As a result, foster and adoptive families are most often not educated about the long-term effects and are unprepared to meet their child’s needs. However, most PSAs require foster parents to take a specified number of educational courses annually. These courses should include education about the effects and developmental needs

of the child with FAS since the majority of foster parents will encounter at least one child with FAS or a related disorder during their time as a foster parent.

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

*Age-specific services.* Basic child development informs clinicians and service providers that the abilities of any one individual change dramatically at different stages of development. Intervention research informs providers that the most effective programs are those that are geared towards an individual's developmental level. There are specific "turning points" during which children demonstrate rapid and fundamental changes in their understanding of the world and in their problem-solving skills (e.g., development of object permanence or acquisition of formal operational thought). The services identified in the following sections include those for both the child and the family, grouped broadly by developmental stage. It is recognized that many of these services span beyond a single age category with considerable overlap, especially for the family.

*Prenatal services.* Significant development of all major organ systems occurs throughout gestation; thereby, making it imperative that women who drink during pregnancy be identified by the medical community as early as possible and be provided intervention services. Findings have indicated that children born to women who stop drinking at any point during their pregnancy have better outcomes than those who continue to drink throughout pregnancy (73). To ensure this happens, physicians, nurses, and other allied health professionals need to be trained to screen patients for possible alcohol use, to understand the detrimental effects of prenatal exposure to alcohol, to understand alcoholism as a treatable disorder, and to be familiar with treatment services. Many women who drink during pregnancy and their partners are not educated about FAS or the harmful effects of drinking during pregnancy. These prospective parents might not be prepared to address their shame or the needs of their children. Some women who experience an alcohol-exposed pregnancy might have been exposed themselves prenatally to alcohol. Therefore, treatment personnel need to be educated about both FAS and needed services to provide more appropriate treatment, as well as provide ongoing support and monitor these families closely.

*Services for birth to 3 years of age.* The first years of life are an important time for physical, cognitive, and emotional development. Decades of research have consistently shown the benefits of early intervention for children with developmental disabilities. Clinicians working with this age group need to familiarize themselves with the state systems that service this population. In particular, Part C of the Individuals with Disabilities Education Act (IDEA) provides early intervention for children 0 to 3 years of age. In many states, this program is administered through local health departments. A particularly appealing aspect of the Part C portion of IDEA is that FAS is considered a "presumptive eligibility" diagnosis. Presumptive diagnoses allow children "at risk" of later develop-



mental delay to be served without meeting particular eligibility criteria. That is, children who are at risk for later developmental problems can receive services, even if they test in the normal range or do not meet other eligibility criteria. This is very important for children with FAS because only about 25% score in the significantly developmentally delayed range (or the range of mental retardation for older children; 95). Referring children who have the FAS diagnosis as well as children who are exposed but do not meet the full diagnostic criteria for FAS, ensures that these children are monitored and, at appropriate ages, referred to appropriate ancillary services as needed. Many states maintain birth defects registries that track the ICD-9 code encompassing FAS (i.e., 760.71 Fetal Alcohol Syndrome) which also can facilitate such monitoring. All infants who are known to have been exposed prenatally included in these registries can be referred to the state's special child health services (note: each state will have its own name for this service) that are part of all states' maternal and child health systems. Special child health services programs provide case management and referral services for children with birth defects or developmental disabilities as well as facilitate evaluation for early intervention programs.

As noted previously, a stable and nurturing caregiving environment is a protective factor for children with FAS. Child development literature states that stable and nurturing environments promote secure attachments between infants and caregivers (144). Secure attachment facilitates emotional, social, and personality development in positive ways. Insecure or negative attachment can lead to inappropriate development in these areas, and at the most severe end of the continuum, the psychopathology of reactive attachment disorder (RAD). The time between birth and 3 years of age has been shown to be a particularly salient time for development of child and caregiver attachment. Disruption in the caregiving environment can lead to poor or negative attachment between infant and caregiver (145). Because many children with FAS are in the foster care system and experience multiple placements (due both to the nature of the system and the difficulty in parenting a child with FAS), they are at tremendous risk for negative attachment including RAD.

*Services for children 3 to 6 years of age and school age.* It is often during the toddler period that children with FAS will be identified and can be diagnosed. It is essential that states establish FAS diagnostic centers or ensure that their child evaluation centers have clinicians who are trained in the dysmorphic and other diagnostic criteria associated with prenatal exposure.

Following the families themselves, the educational system serves as the most constant service provider for individuals with FAS from early childhood through adolescence. Therefore, beginning with preschool programs and through secondary education, generalized essential services can be delineated. When a child reaches three years of age, early intervention services (IDEA Part C) end and families are referred to preschool handicapped programs (sometimes called special needs preschool) that are administered through IDEA Part B. Part B of IDEA differs from Part C in that there are no presumptive eligibility diagnoses. Eligibility for educational services under this program is related entirely to functional criteria and their relation to educability. As noted previously, this can make it difficult for children with FAS to qualify for these special education services because only a quarter of the children with FAS achieve standardized test scores in the range of significant developmental delay (or mental retardation), the usual eligibility threshold. However, within the IDEA framework, there are a few categories that allow children with FAS who score above the eligibility threshold to still qualify. A few children with FAS will qualify in the category of learning disabled (LD). This category is for children who demonstrate a statistically significant discrepancy (2 standard deviations or more) between overall IQ and one or more academic skills (e.g., math).



Another eligibility category that has been helpful in qualifying children with FAS is behavior disorder. However, this category should be used with care because children with FAS can learn negative behaviors from other children without receiving the benefits of a structured environment. Finally, the category of other health impaired (OHI) can be used at the discretion of the individual education plan (IEP) committee, which includes parents as well as school personnel. Services available through the school system go beyond classroom settings. Children can receive various therapies, including physical therapy (usually most appropriate for very young children), speech and language therapy, occupational therapy, or social skills training. These last two areas are particularly helpful to children with FAS because of the visual-motor deficits and problems in social interactions they encounter.

Training parents to be effective educational advocates is essential to maximize the benefits of their child's special education and to understand their child's rights. The purposes of the IEP are to insure access to appropriate habilitation and rehabilitation services (physical, occupational, speech, behavioral, mental health, and other related services) and to ensure that academic curricula are balanced with vocational training and skills of daily living (e.g., personal hygiene, money management, and family life education), when appropriate. In addition to training parents about the educational system, the preschool period, as well as elementary school years, are times when parents become more acutely aware of their child's imitations. Reinforcement and updating of information learned in early parent education settings will benefit both the child and the parents. Reviewing lessons learned will help parents adjust their expectations for the child's current functioning, as well as his or her future possibilities.

As noted previously, it is important that school staff be trained to recognize possible characteristics associated with FAS, as well as appropriate techniques for instructing students with FAS. Irrespective of whether alcohol-exposed children are in regular or handicapped preschool programs, educational methodologies need to be developed that best address their learning styles and that appropriate behavioral or mental health services are available and initiated.

Beyond services available through the educational system, families raising preschool and school-aged children continue to need services to promote positive family functioning. Such services might include behavior management training, family (or child) counseling, parenting workshops that focus on the unique aspects of parenting a child with FAS, or other types of continuing education. One service that becomes very important during these years is respite care. Such care allows a trained individual to stay with the affected child while caregivers or other family members take advantage of some time away from the child with FAS. Respite care has been shown to significantly reduce family stress and improve family functioning (146-147). Unfortunately, respite care, especially formalized and high-quality respite care, is not readily available in most communities. A clinician can help in this situation by working with the family to develop informal respite care situations, such as help from an extended family member working with the family and to provide the necessary education about FAS to such a respite care provider.

*Services for adolescents.* Adolescence, and even preadolescence, is one of the major turning points in the life of an individual with FAS. His or her body is changing, cognitive abilities are changing, peer groups are changing, and community expectations are changing. Because of the confusing nature of all these changes, adolescence often is the period when behavioral and mental health problems become more pronounced. Depression or anxiety, or both, can set in as the individual

struggles to cope with these changes. Increased opportunities to experience alcohol and/or drugs can lead to substance abuse problems. Families could become involved with juvenile or criminal justice systems. These are some of the most serious secondary conditions that research has identified for individuals with conditions associated with prenatal alcohol exposure (95).

It is often during adolescence that families experience high levels of stress and tension. As such, the need for individual counseling (for both child and parent), family counseling, and a strong support network becomes more crucial. However, this can be the exact stage at which agencies are reluctant to provide such services, especially if the FAS-related disability factor is not recognized. Because some amount of rebellion is expected during adolescence, the challenging behaviors of the teenager with FAS might be dismissed as transient. At the other end of the spectrum, the challenging behaviors of the adolescent with FAS can be so severe as to involve the criminal justice system.

Because adolescents will soon be leaving the safety and structure of the educational system, vocational and transitional services become essential during this stage. These services often represent a shift from academic skills and achievements to daily living skills, including employment skills. It is very important that these services be started in early adolescence, and not left until the individual is about to age-out of the educational system. In addition, beyond teaching the specific skills that go with a particular job, it might be necessary to explicitly teach those skills related to being a good employee (e.g., punctuality and minimized socializing). Most individuals will learn these skills through basic maturity and observational learning. Individuals with FAS often need explicit instruction as well as lifestyle supports (e.g., a job coach).

As for all adolescents, sexual behavior often becomes a critical issue during this stage. The boundaries for appropriate interaction with the opposite sex, the subtle nature of social cues, and impulse issues are difficult for any adolescent, but more so for the adolescent with FAS. Close supervision is the first line of defense during the adolescent years. However, such supervision often conflicts with the adolescent's growing desire for independence. This must be navigated with care to avoid alienating the adolescent. Also, it is probably best to be open and explicit with the teenager with FAS concerning the issues of contraception, sexually transmitted diseases, and sexual harassment. Failure to address these issues can have serious, and possibly life-threatening consequences for the affected individual, his or her family, and any children resulting from unintended pregnancies.

As mentioned previously, individuals with FAS are at high risk for involvement with the juvenile and criminal justice systems. Their lack of executive functioning skills (i.e., poor judgment), fluid language skills, and naïve social skills make them particularly vulnerable to participating in criminal activity. However, these same deficits demand that when they do encounter the justice system, their deficits should be taken into account during all aspects of justice proceedings (i.e., charges, process, punishment, and rehabilitation). As such the juvenile and criminal justice systems are major social systems in need of education regarding FAS. Special rehabilitation programs with staff that are trained to work with adolescents and young adults with FAS should be established. Such programs should be based on scientifically-based research findings that evaluate practicality as well as effectiveness.

*Services for adults.* In addition to all the services mentioned for the preceding age groups, adults with FAS often need support in every area of their lives. Everyday needs such as transportation issues, job assistance, housing assistance, medication reminders, money assistance, and support and

assistance when unpredicted issues arise should continue to be monitored and supported. Although not consistently available, clearly a system needs to be established that assists people with FAS in living as independently in the community as possible and includes support for housing, healthcare, and employment.

Because of federal, and often state legislation, it is very difficult for people with FAS to receive services from state developmental disability agencies, unless exposed individuals have met the eligibility criteria for services before 22 years of age. Eligibility criteria are generally based on levels of intelligence, as well as functional limitations in at least three areas associated with skills of daily living. As a result, many exposed individuals will not be eligible for services that often include an individual service plan (ISP), case management, residential and employment assistance, and possibly social security disability payments.

People with FAS might be eligible for federal assistance, such as, Medicaid, Supplemental Security Income (SSI), and Section 8 Housing subsidies, not because of their disabilities but because of their low income status. However, obtaining these services can be difficult. For example, most states have long waiting lists for Section 8 housing because of both the high demand and great need often leading to a shortage of rental units. Eligibility criteria for these services, even when based on income, should include a priority category for persons with FAS. Unfortunately, many of these housing options do not offer the support and structure that adults with FAS often need. Housing remains one of the main issues in supporting individuals with FAS for which there are no appropriate services developed or identified.

## **IDENTIFYING AND INTERVENING WITH WOMEN AT RISK FOR AN ALCOHOL-EXPOSED PREGNANCY**

Despite ongoing efforts to inform childbearing-aged women of the risk associated with alcohol use during pregnancy, surveys conducted by the CDC and SAMHSA indicate that 9% to 12% of pregnant women in the United States report consuming alcohol and that approximately 3% report drinking at levels that have been consistently associated with adverse effects on the fetus (148-149). Also of concern are the high proportions of non pregnant childbearing-aged women whose drinking patterns exceed safe levels as defined by public health agencies (150-151). Currently more than half of all women of childbearing age (18 through 44 years of age) report alcohol use, and one in eight report binge drinking in the past month. Many of these women are sexually active and are not taking effective measures to prevent pregnancy. These women are at risk for an alcohol-exposed pregnancy in that they could have an unrecognized pregnancy and continue drinking early in pregnancy at levels that are harmful to the fetus.

One public health strategy for preventing alcohol-exposed pregnancies is to identify characteristics of women at greatest risk of having a child affected by prenatal alcohol exposure and implement prevention programs in subpopulations with higher proportions of these identified risk factors. Over the past 20 years, concerted efforts have been made to identify factors among childbearing-aged women associated with harmful patterns of alcohol consumption. One extensive review of studies reporting characteristics of women giving birth to a child with FAS found that low socioeconomic status (SES), African-American and American-Indian/Alaska-Native ethnicity, and being a smoker were characteristics commonly found among women in this group (152). Additional studies using cross-sectional survey data and special populations have extended our understanding of char-

acteristics associated with childbearing-aged women at high risk for having an alcohol-exposed pregnancy based on current drinking patterns. Factors associated with risk include being a smoker, having a low SES, being unmarried, having a history of previous or current illicit drug use, having a history of physical or sexual abuse, having psychological stress, and having mental health disorders (153-156). In an attempt to identify community-based settings that have higher proportions of pre-conceptional women at increased risk for an alcohol-exposed pregnancy, CDC sponsored an epidemiological study of special populations that included: women in alcohol and drug treatment centers, a large urban jail, publicly funded primary care clinics, a university-based gynecology clinic in a large urban hospital, and a cohort of women responding to a newspaper solicitation (27). Being at risk for an alcohol-exposed pregnancy correlated significantly with being (or having ever been) a smoker, having a history of inpatient treatment for drugs or alcohol, having a history of inpatient mental health treatment, having multiple sex partners, and having experienced recent physical abuse.

Primary prevention of alcohol-exposed pregnancies requires the accurate identification of women who are drinking at thresholds that have been associated with adverse pregnancy and infant outcomes before pregnancy occurs. Dietary guidelines from the U.S. Department of Health and Human Services recommend that women drink no more than one drink per day to avoid increased risk for adverse health conditions and that women who are pregnant, planning a pregnancy, or at risk of pregnancy abstain from alcohol use altogether. Research findings support these recommendations with evidence of increased risk for birth defects, spontaneous abortions, and deficits in neurocognitive development and growth at levels of seven or fewer drinks per week in some studies (157-162).

Of further concern is the pattern in which alcohol is consumed. Heavy episodic drinking, as in binge drinking, can result in increased severity of the teratogenic exposure effects because of the higher peak blood alcohol levels achieved in this pattern of consumption as opposed to lower level daily consumption (40,163). Historically, a binge episode has been considered to be five or more drinks on any one occasion, but evidence of the presence of gender effects in alcohol metabolism and higher morbidity and mortality among women than men with similar consumption patterns has prompted recommendations for defining a binge episode for women as four or more drinks on any one occasion or on any one day. Current recommendations on clinical thresholds published by the NIAAA are that women drinking more than seven drinks per week or more than three drinks on any given day in the past month be further assessed for risk of developing alcohol-related problems. As stated earlier, pregnant women are advised to abstain from alcohol use. This is a long-standing federal advisory and one supported by major professional societies as well (9,164).

Measurement of current alcohol consumption can be enhanced through the use of reliable screening and assessment methods. A number of screening instruments have been developed that offer the practitioner options for clinical assessment of childbearing-aged women. When selecting a screening tool for routine implementation, healthcare professionals should consider factors such as the goals of the screening process, the target population, and the ease of administration. All women of childbearing age should be screened for alcohol use, including women who are pregnant or nursing, women who are planning a pregnancy, and women who are sexually active and not using contraception (such as teens and college-aged women).

*Methods and Considerations for Establishing Reliable Estimates of Alcohol Use.* Measures most commonly used in alcohol assessment include items that address quantity, frequency, and pattern (variability) of drinking. Quantity-frequency measures (QF) inquire about average or typical consumption patterns. The simplest measures assess the amount of drinking on average drinking days (Q), and the average number of days on which alcohol is consumed (F). QF measures can be used to estimate a woman's average number of drinks per day or the amount of absolute alcohol consumed per day (AA score). To assess for binge drinking, some investigators have recommended that screening questions should include measures of maximum quantity consumption and frequency of maximum quantity consumption (165). *Helping Patients with Alcohol Problems: A Practitioner's Guide*, developed by the NIAAA, (166) recommends quantity-frequency and maximum quantity questions as the primary screening test. These questions have been shown to have relatively high sensitivity and specificity, are easy to use, and can be incorporated into a health practice with minimal cost and effort (167).

Additional considerations for alcohol screening include measurement of the types of alcoholic beverages the woman consumes. The development of new ways of marketing wine and beer, including higher alcohol concentration malt liquors and beer in 20- to 45-ounce containers, has increased the need to provide women who drink with more specific standards to estimate their consumption. Studies show that reliance on standard drink measurements when assessing drinking practices of heavier drinkers or those consuming higher alcohol content beverages can result in considerable underestimation of alcohol consumption (168-169). Moreover, beverage-specific questions have been shown to be more accurate than grouped beverage questions (170).

One of the most reliable assessment tools for gathering accurate self-reported alcohol use is the timeline follow back (TLFB) measure (171). This method of alcohol use assessment typically asks respondents to think back over the past 90 days and report daily drinking amounts during that period of time. Respondents are given a calendar and asked to identify special events that occurred during that time period, such as parties, birthdays, or holidays that might serve to trigger recall of drinking occasions. A major strength of the TLFB measure is its ability to capture both average daily drinking and sporadic drinking that might entail drinking at higher levels of consumption. Because of the time requirements necessary for gathering information using the TLFB approach, it is not easy to use in primary care settings but it has been used in clinical research to establish the reliability and validity of other briefer screening and assessment tools (172).

*Screening Tools.* Several brief questionnaires have been developed over time to screen for problematic alcohol use in adults in diverse populations and settings. Screening tools currently in use include the CAGE, AUDIT, T-ACE, TWEAK, MAST, S-MAST, NET, RAPS4, and RAPS4-QF (173). The CAGE (174) is a four-item alcohol use measure designed to detect alcoholism and is one of the most commonly used screening instruments for men and women. The four questions ask the respondent: (C) Have you ever felt you should CUT down on your drinking? (A) Have people ever ANNOYED you by criticizing your drinking? (G) Have you ever felt bad or GUILTY about your drinking? and (E) Have you ever had a drink first thing in the morning to steady your nerves or to get rid of a hangover (EYE OPENER)? Each item is scored as a 0 (no) or 1 (yes) and scores of 2 or greater are considered clinically significant.

The AUDIT is a 10-item self-report questionnaire developed by the world health organization (WHO) for identifying individuals whose alcohol consumption has become hazardous or harmful



to their health (175). The items on the AUDIT are constructed to measure frequency of alcohol consumption, dependence symptoms, and the personal and social consequences of drinking. The first three questions of the AUDIT address the quantity, frequency, and maximum amount of alcohol consumed. The remainder of the questionnaire has two items from the CAGE, (feelings of guilt about drinking and the need for a drink first thing in the morning after a heavy drinking session—eye-opener) in addition to questions on the frequency of being unable to stop drinking once drinking starts, frequency of being unable to do what is normally expected because of alcohol use, frequency of memory loss of the previous night due to drinking, frequency of injury to self or others as a result of drinking, and frequency of others expressing concern over the individual's drinking (a relative, friend, or doctor). A score of eight or more is considered significant for high-risk consumption. The measure has good psychometric properties and has an advantage over other screening tools in that it measures not only experienced consequences of drinking, but also whether an individual is currently drinking at levels likely to eventually result in problems (176). The instrument has been used and validated in cross-cultural populations (177). One review of 38 studies on screening for alcohol problems in women and men in primary care settings found the AUDIT was more effective in identifying individuals with at-risk, hazardous, or harmful drinking patterns, while the CAGE proved superior in detecting alcohol abuse and dependence (178). Another study of women who were receiving outpatient care through the Veterans' Administration found that the AUDIT-C (comprised of the first three items of the AUDIT on quantity, frequency, and maximum drinks per drinking occasion) proved to be more sensitive than the full 10-item AUDIT (179). Such findings suggest that when time of administration is a consideration, the shorter AUDIT-C might be used as the screener of choice.

Two screening tools that have been specifically developed and used with pregnant women are the T-ACE and the TWEAK (180-183). The T-ACE has four questions that take less than a minute to ask. The questions are: (T) TOLERANCE, how many drinks does it take to make you feel high? (A) Have people ANNOYED you by criticizing your drinking? (C) Have you ever felt you ought to CUT DOWN on your drinking? (E) EYE OPENER, Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover? One point is given for each affirmative answer to the A, C, E questions, two points when a pregnant woman reports a tolerance of more than two drinks to feel high. A positive screen is a score of two or more points. The T-ACE has been shown to be an efficient screen for risk drinking in pregnant women and out-performs medical staff assessment alone (184). Its brevity (four-items) is an important asset and increases its utility for clinical practice.

Like the T-ACE, the TWEAK attempts to elicit information on the following: (T) TOLERANCE for alcohol; (W) WORRY or concern by family or friends about drinking behavior; (E) EYE OPENER, the need to have a drink in the morning; (A) "blackouts" or AMNESIA while drinking; and (K) the self-perception of the need to CUT DOWN on alcohol use. Scores range from zero to seven. The tolerance and worry questions each contribute two points and the other three questions contribute one point each. Any endorsement of the worry question is scored a two. On the tolerance question, if three or more drinks are needed to feel high, the question is scored as a two. Other versions of the tolerance question ask: How many drinks does it take before the alcohol makes you fall asleep or pass out? Or, if you never drink till you pass out, what is the largest number of drinks you have or can hold? These questions are scored as a two if the woman answers five or more drinks. Using these questions, however, results in lower sensitivity and specificity. A total score of three or more on the TWEAK is suggestive of harmful drinking patterns (185).



Studies assessing the relative effectiveness of various screening tools have yielded different findings depending on the populations studied. Bradley et al. (186) summarized data from 13 published, peer-reviewed articles that contained information on the performance of alcohol screening questionnaires with non pregnant women and with obstetric patients during the periconceptional period. The results revealed that, for non pregnant women, the CAGE had low sensitivity in predominantly White female populations, but was a reasonable choice for identifying past year or lifetime alcohol dependence in predominantly African American female populations. Overall, the five-item TWEAK appeared to be the optimal screening questionnaire for identifying heavy drinking or alcohol abuse and dependence in racially mixed populations of non pregnant and pregnant women.

Some clinicians have suggested that the use of screeners best suited for identifying high-risk heavy drinkers might not be optimal for identifying pregnant women with irregular or lighter patterns of consumption that might still pose a risk for fetal development. Using confidential reporting procedures, one study examined the effectiveness of the TWEAK for assessing any report of drinking following pregnancy recognition in a group of low-income pregnant women participating in WIC (187). With a cut point score of two or greater, the specificity of the TWEAK was high for all ethnic groups studied; however sensitivity, while high for White non-Hispanic women, was low for African-American non-Hispanic and Hispanic women. Because any endorsement of alcohol use was sufficient for classification as a drinker in this sample, low sensitivity on the TWEAK might have been due to the fact that women were drinking at levels that were too low to result in alcohol-related problems but, were still high enough to be detrimental to the developing fetus. From a practical standpoint, the high specificity of the TWEAK supports its utility in busy clinic settings. High specificity suggests the TWEAK is effective in screening women who are not high risk, and as shown in the study cited previously, women who report not drinking at all. Nevertheless, the fact that the TWEAK had variable sensitivity for women from different ethnic backgrounds suggests that additional methods of screening should be employed in order to increase the detection of women who might need intervention.

Drinking among adolescents and college students has long been recognized as a significant problem with far-reaching public health implications (188-189). Although the most problematic drinking in adolescence has been documented among males when compared to females, alcohol use in females has been associated with decreased use of contraception (increasing the likelihood of an unintended pregnancy), increased sexual assault, and more sexually transmitted diseases. Because of these significant negative health consequences, the American Medical Association Guidelines for Adolescent Preventive Services recommend screening of adolescents for alcohol and other drug use as part of routine medical care (190). To effectively screen adolescents, the ideal screening tool must be developmentally appropriate and practical for use in busy medical offices or clinics. Although the CAGE and the AUDIT are relatively brief, their developmental appropriateness is questionable. Indeed, current research suggests that the CAGE is not appropriate for screening adolescents and that a much lower cut point of two (rather than the eight recommended for adults) on the AUDIT is optimal for identifying alcohol use problems in this population (191).

Several measures have been developed specifically for use with adolescents, such as the Rutgers Alcohol Problem Index (192) and the College Alcohol Problem Scale (193); however, these tools might not be practical for universal screening. One brief screening device, the CRAFFT, developed for adolescents, is simple to score, inquires about alcohol and drug use, and was found to have good psychometric properties in a sample of predominately female youths 14 through 18 years of age

(194). CRAFFT is an acronym for the first letters of key words in the test's six questions: (C) Have you ever ridden in a CAR driven by someone (including yourself) who was high or had been using alcohol or drugs? (R) Do you ever use alcohol or drugs to RELAX, feel better about yourself, or fit in? (A) Do you ever use alcohol or drugs while you are by yourself, ALONE? (F) Do you ever FORGET things you did while using alcohol or drugs? (F) Does your family or FRIENDS ever tell you that you should cut down on your drinking or drug use? (T) Have you ever gotten into TROUBLE while you were using alcohol or drugs? Each question on the CRAFFT is given a score of one and a cut point of two provides moderate sensitivity (.70) and excellent specificity (.94) for identifying alcohol use disorders in adolescents. The authors CRAFFT recommend that any positive answer on this measure be followed by further assessment of quantity, frequency, and pattern of use to increase sensitivity and to guide decisions about the need for intervention.

A number of studies have shown a strong association between alcohol intoxication and trauma (195). The Trauma Questionnaire was developed to screen patients in an unobtrusive way without asking them directly about their alcohol use (196). The questionnaire consists of four questions asking about injuries in the last five years (fractures or dislocations of bones or joints, traffic accidents, head injury, or injury during a fight or assault). The questionnaire has been shown to have high sensitivity and specificity for identifying high-risk alcohol use and to be acceptable to respondents and physicians.

*Computer-Assisted Interviews and Laboratory Screening Measures.* The method of delivery of questions about alcohol use has been shown to influence truthful reporting. Clinical interviews might not be as effective in eliciting truthful responses from women because practitioners are not always comfortable asking these questions in a face-to-face interview. Moreover, women could underestimate their alcohol use because of reluctance to discuss this potentially sensitive subject. For this reason, self-administered questionnaires might improve the validity of self-report.

The Audio Computerized Self-Report Interview has been successfully used in prenatal clinics serving disadvantaged low-literacy minority women (197). Questions asked by a recorded voice through earphones are drawn from the TWEAK with quantity and frequency questions pertaining to three months before and during pregnancy are included. Acceptability studies have revealed that patients liked this method of screening.

Laboratory screening measures offer promise for obtaining objective evidence of problem drinking (198-199). The most common biomarkers are gamma glutamyltransferase (GGT) and carbohydrate-deficient transferrin (CDT). Fatty acid ethyl esters synthase (FAEE) can be found in the hair of alcohol using women. This biomarker could hold promise for screening for alcohol use in pregnant women, although the dynamics of enzyme expression appear to be complex and changes occur only at high alcohol doses. Low sensitivity in non alcoholic women and the high cost of laboratory analysis make these measures less feasible for use in more universal screening.

*Brief Intervention.* Brief intervention (BI) has been shown to be a low-cost, effective treatment alternative for alcohol problems that uses time-limited, self-help, and preventative strategies to promote reductions in alcohol use in nondependent individuals, and in the case of dependent people, to facilitate their referral to specialized treatment programs (200-203). Overall, BI for alcohol problems has been shown to be more effective than no intervention and often as effective as more extensive intervention (204). Effective prevention programs frequently employ a multicomponent

approach combining cognitive-behavioral techniques with norms clarification, education, and motivational enhancement interventions. BI is usually restricted to fewer than four sessions and is typically performed in a treatment setting that is not specific for alcoholism. It is often performed by personnel who are not specialists in the treatment of alcohol use and abuse, and is provided to individuals at varying levels of risk for negative consequences because of drinking, rather than those who are considered alcohol dependent (205).

Six elements characterize the key ingredients of standardized brief intervention summarized by the acronym FRAMES (206). These are: Feedback of personal risk, Responsibility for personal control, Advice to change, Menu of ways to reduce or stop drinking, Empathetic counseling style, and Self-efficacy or optimism about cutting down or stopping drinking. The intervention also involves establishing a drinking goal in the form of a signed contract and follow up of progress with ongoing support. Studies reveal that supportive, nonjudgmental techniques in which trained personnel counsel women can lead to decreased alcohol consumption during pregnancy. The most effective intervention approaches avoid the use of moral or volitional injunctions and instead focus on reduction of alcohol use without criticism or provocation of guilt (205). Effective interviewers have been found to have a thorough knowledge of the intervention technique, an optimistic attitude about change, a compassionate style, genuineness and respect for clients, an ability to avoid arguments that evoke patient defensiveness, and comfort discussing alcohol problems (207-208).

*Motivational Interviewing.* A technique often used in brief interventions is motivational interviewing (MI). MI uses an empathic, client-centered counseling approach to increase readiness for change by resolving ambivalence about behavior change (207). The process explores the client's ambivalence in an atmosphere of acceptance, warmth, and positive regard. Although the session is structured and to the point, direct persuasion and coercion are avoided. The goal is to enhance the discrepancy between the reasons for changing versus staying the same. More than 24 studies of MI have found beneficial effects in decreasing problem drinking and other health-related problem behaviors (209).

*Manualized Brief Intervention.* Although the findings of the previously cited studies provide the foundation for intervention and prevention efforts, the usefulness of MI in a busy clinic or medical practice might be limited in that it requires additional training and clinical skills development. Recently, standardized manualized BI techniques to reduce alcohol consumption have been developed. One such intervention is Project CHOICES (Changing High-risk alcohol use and Increasing Contraception Effectiveness Study), which is funded by CDC. Project CHOICES is an example of a brief intervention using motivational interviewing techniques aimed at preventing alcohol-exposed pregnancies among high-risk women in various community settings (210). This project focused on both alcohol risk reduction and pregnancy postponement until alcohol use was decreased in a group of non pregnant women who were of childbearing age, fertile, sexually active, and using ineffective or no contraception. Phase I results revealed that at six-month follow up, 68.5% of the women were no longer at risk of having an alcohol-exposed pregnancy, 12.6% had reduced their drinking only, 23.1% reported using effective contraception only, and 32.9% reported doing both. A Phase II randomized controlled trial is currently underway testing the efficacy of this approach and is slated for completion in fall 2004. Another recent CDC-funded study still underway is Project Balance, which uses a briefer adaptation of Project CHOICES and is aimed at female college students, encouraging them to abstain from alcohol or to use contraception if they drink.

Four randomized controlled studies, funded by NIAAA, serve as further examples of the utility and effectiveness of this approach. These studies included women of different socioeconomic and cultural backgrounds and were conducted in doctors' offices and community settings. Two of the studies found that manualized BI was successful in decreasing alcohol use during subsequent pregnancies in high-risk women, thus preventing possible negative developmental sequelae in their offspring (211). The other two studies, one working with high-risk, White, middle class pregnant women in physicians' offices and one working in WIC community clinics with primarily low risk, low-income Hispanic clients, also found manualized BI to be a promising approach (212-214). In the WIC study, better infant outcomes were reported, including longer birth lengths and a lower infant mortality rate. Significantly, in both studies, the control conditions that included an assessment of alcohol consumption and simple advice to stop or cut down on drinking were almost as effective as the manualized BI itself. The success of these projects in reducing alcohol consumption in both experimental and control groups was postulated to be due to the desire of pregnant women to have healthy pregnancies and to the time and attention that interventionists provided for women in both groups.

*Computerized Brief Intervention* One recently developed study is investigating the use of a computerized method of a BI that incorporates the use of vessel size and normative education that allows a woman to evaluate her own consumption levels (169). Once a woman has been educated about her consumption levels, she then participates in a standardized BI. This approach is promising in that it incorporates many recommended aspects of screening, educating, and assisting women in recognizing that they might have a drinking problem, and then providing a brief intervention. The automated computerized assessment is designed for use in prenatal clinics and is currently being tested at a large HMO through an NIAAA grant. Although the effectiveness of this intervention has yet to be validated, it offers a potentially useful method that could be expanded nationally.

*Improving Use of Screening and Brief Intervention Technology by Clinicians.* Research devoted to finding ways to encourage clinicians to use brief interventions indicates that routine educational approaches might not be effective. Effective strategies include (1) conducting educational programs at the intervention site; (2) using specific step-by-step, evidence-based clinical protocols; (3) using skills-based role playing; (4) holding peer group discussions; and (5) using a credible expert trainer or educator. Brevity, repetition, and reinforcement of recommended practices are also key program elements (215). In an effort to enhance physician uptake of current screening and intervention approaches for preventing alcohol-exposed pregnancies, the NIAAA and the Office of Research on Minority Health recently collaborated in the development of a guide for primary care providers for screening pregnant and non pregnant women on selected health behaviors, including alcohol use, and recommendations for appropriate advice depending on the level of alcohol use and consequences (166). More recently, CDC funded four regional training centers on FAS to provide education and training to medical and allied health professionals and students about identification and diagnosis of children affected by prenatal alcohol exposure and effective approaches for intervening with and preventing these conditions. More information about these and other resources can be found by accessing the websites provided at the end of this section.

Universal screening for alcohol use should be conducted among all women of childbearing age. Screening can be done in both physicians' offices and in community health settings. Simple screening techniques that include measures of quantity, frequency, and heavy episodic drinking, as well as

behavioral manifestations of risk drinking, have proven to be most beneficial. For non pregnant women, the AUDIT, TWEAK, and CAGE have been found to be useful screening tools depending on the population characteristics of the community as described in the studies reviewed earlier. However, studies on gender-specific modifications of these screening tools have been recommended because women report increased psychosocial problems at lower levels of consumption than men. Based on some empirical evidence, reduced cut points for women have been recommended, including a cut point of 4 or more for the AUDIT, 2 or more for the TWEAK, and 1 or more for the CAGE (186). For pregnant women, the T-ACE and the TWEAK are the recommended screening tools of choice. The CRAFFT shows promise as an alcohol and other drug screener for female adolescents. Findings support better identification when screening instruments are used versus clinical assessment alone. Brief interventions administered by physicians and allied health professionals in medical and non medical settings are effective in bringing about reductions in drinking.

Women who are pregnant, planning a pregnancy, or at risk of pregnancy should be advised not to drink, as no safe threshold of alcohol use during pregnancy has been established. Non pregnant childbearing-aged women should be advised to drink no more than seven drinks per week and no more than three drinks on any one occasion.

Both BI approaches and MI techniques have been found to be efficacious with pregnant and non pregnant women in promoting reduction in alcohol consumption. Furthermore, some evidence suggests pregnant women are motivated to stop drinking even if the intervention includes only an assessment of alcohol use with simple advice to stop or reduce drinking. Research also indicates that interventions are effective with pregnant women who are light as well as high-risk drinkers. Moreover, preconceptional counseling of women of childbearing age who are at risk for an alcohol-exposed pregnancy and who are not using effective contraception has been demonstrated as a promising method of prevention as well as computerized versions of standardized methods of intervention. This year the U.S. Preventive Services Task Force released recommendations calling for use of the screening and behavioral counseling interventions for adults in primary care setting, including pregnant women (216-217). These evidence-based recommendations mirror the content of these guidelines with respect to the specific types of screening tools recommended and the components of effective brief interventions to be used. The recommendations of the U.S. Preventive Services Task Force, which is supported by the federal Agency for Healthcare Research and Quality, provide further support for the need for widespread public health implementations of these prevention technologies to reduce the harmful consequences of alcohol misuse, including FAS and other prenatal alcohol-related conditions. Information about reported and other federally sponsored studies in FAS and prenatal alcohol screening and intervention can be obtained at the following websites: [www.nih.gov](http://www.nih.gov); [www.cdc.gov](http://www.cdc.gov); [www.samhsa.gov](http://www.samhsa.gov); and [www.preventiveservices.ahrq.gov](http://www.preventiveservices.ahrq.gov).

## **SUMMARY AND FUTURE STEPS**

In 2002, CDC was congressionally mandated to develop diagnostic guidelines for FAS and other prenatal alcohol-related disorders and integrate them into medical and allied health education.



With input from a SWG composed of clinicians, experts, and families, and from the NTFFAS/FAE, scientific and clinical evidence was reviewed to develop guidelines that offer a balance between conservative and overly inclusive definitions of FAS. Criteria for conditions not meeting the clinical definition of FAS (e.g., ARND) were not established because scientific evidence is insufficient at this time. Clinical and scientific research on FAS and those conditions resulting from prenatal alcohol exposure that do not meet the criteria for an FAS diagnosis is currently underway. These findings and advances will contribute to further refinement of the FAS criteria, and could potentially delineate additional diagnostic categories and criteria for conditions other than FAS. The development of these FAS guidelines is a continuous process. Efforts to develop and refine other diagnostic categories to identify FAS and related conditions need to continue.

During this guidelines development process, several key issues emerged that deserve mention.

1. More information on the neurodevelopmental effects of prenatal exposure to alcohol is needed. Particular emphasis should be placed on finding the unique aspects of FAS that will help differentiate it from other birth defects or developmental disabilities, or both.
2. Efforts to improve the clinical assessment tools (e.g., facial and growth measures) used to diagnose FAS should continue, particularly in terms of racial and ethnic variations and age.
3. All children should be screened for the possibility of an FAS diagnosis. As physicians and other allied health professionals become educated about this disorder, screening for FAS should become routine.
4. Better communication between obstetricians, gynecologists, and pediatricians is needed to improve documentation on prenatal alcohol use. This would help with the diagnosis of prenatal alcohol exposure in the child and could help identify women at risk for future alcohol-exposed pregnancies.
5. Service agencies must provide a way to qualify children with FAS and related disorders who do not meet their traditional eligibility requirements.
6. Further research and resources are needed to identify and treat women at risk for an alcohol-exposed pregnancy.
7. Awareness, both in the public and professional arenas, about the dangers of drinking alcohol during pregnancy and about FAS and how the condition affects children and their families is essential. A key avenue to avoiding FAS is active promotion of programs to increase awareness of the dangers of drinking alcohol during pregnancy and promotion of prevention activities that increase understanding of the risks of alcohol as well as the risks for an alcohol-exposed pregnancy.

Over 30 years ago, researchers first described FAS. Much has been learned about the disorder since that time, as is reflected in these guidelines. However, there is still much more to learn about the entire spectrum of effects from prenatal alcohol exposure. Future work will address these gaps. To reduce FAS and other prenatal alcohol-related conditions, the key is prevention. Federal, state, and local agencies; clinicians and researchers; educational and social service professionals; and families



need to work together to educate women of childbearing age and communities across the country about the risks of drinking alcohol during pregnancy.

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## **Notes**



## **Notes**



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To learn more about Fetal Alcohol Syndrome, contact:

## **FAS Inquiries**

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