382 Fetal Alcohol Spectrum Disorders

Definition/Cut-off Value

Fetal alcohol spectrum disorders (FASDs) are a group of conditions that can occur in a person whose mother consumed alcohol during pregnancy (1). FASDs is an overarching phrase that encompasses a range of possible diagnoses, including fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related birth defects (ARBD), alcohol-related neurodevelopmental disorder (ARND), and neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE) (2).

Presence of condition diagnosed, documented, or reported by a physician or someone working under a physician's orders, or as self-reported by applicant/participant/caregiver. See Clarification for more information about self-reporting a diagnosis.

Participant Category and Priority Level

Category	Priority
Pregnant Women	I
Breastfeeding Women	I
Non-Breastfeeding Women	III, IV, V or VI
Infants	I
Children	III

Justification

Prenatal exposure to alcohol can damage the developing fetus and is the leading preventable cause of birth defects and intellectual and neurodevelopmental disabilities (2). (See risk #372 *Alcohol and Substance Use* for more information.)

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother consumed alcohol during pregnancy (2). These effects include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications (1, 2). Often, a person with FASD has a mix of these conditions (1).

The term FASDs is *not* meant for use as a clinical diagnosis and encompasses all other diagnostic terms, such as fetal alcohol syndrome (FAS) (1, 2). FASDs refer to the whole range of effects that can occur in a person whose mother consumed alcohol during pregnancy. These conditions can affect each person in different ways and can range from mild to severe. A person with FASD might have any or a combination of the following conditions (1):

- Facial abnormalities, such as a smooth ridge between the nose and upper lip (this ridge is called the philtrum).
- Small head size, short stature, low body weight.
- Sleep and sucking problems as an infant.

- Hyperactive behavior, difficulty with attention, poor memory, difficulty in school (especially with math), learning disabilities, poor reasoning and judgment skills.
- Poor coordination, speech and language delays, intellectual disability or low IQ.
- Problems with the heart, kidneys, bones, vision, or hearing.

The severity of alcohol's effects on a fetus primarily depends on the following (3, 4):

- Quantity – the amount of alcohol consumed by a pregnant woman per occasion.
- Frequency – the rate at which alcohol is consumed or is repeatedly consumed by the pregnant woman.
- Timing – the specific gestational age of the fetus when alcohol is consumed by the pregnant woman.

Fetal Alcohol Spectrum Disorders Diagnoses

Different terms are used to describe FASDs, depending on the type of symptoms.

Fetal Alcohol Syndrome (FAS) was the first form of FASD discovered and is the most well-known. It represents the most involved end of the FASD spectrum. A diagnosis of FAS requires evidence of prenatal alcohol exposure; evidence of central nervous system (CNS) abnormalities (structural or functional); a specific pattern of the following three facial abnormalities: narrow eye openings, a smooth area between the lip and the nose (vs. the normal ridge), and a thin upper lip; and growth deficits either prenatally, after birth, or both (1). Fetal Alcohol Syndrome can affect children in different ways. A child with FAS may have problems with learning, memory, attention span, communication, vision, and/or hearing (3). Also, people with FAS often have a hard time in school and trouble getting along with others (1).

The Centers for Disease Control and Prevention worked with a group of experts and organizations to review the research and issued guidelines for diagnosing FAS in 2004. The guidelines were developed for FAS only. Diagnosing FAS can be challenging due to other medical disorders, such as attention deficit/hyperactivity disorder (ADHD) and Williams syndrome, having similar symptoms and the lack of standard medical tests. (1)

Partial FAS (pFAS) involves prenatal alcohol exposure and includes some, but not all, of the characteristics of full FAS (3). A diagnosis of pFAS requires a confirmed history of prenatal alcohol exposure and CNS abnormalities at the same level as FAS. Individuals with pFAS sometimes have growth deficiency or one or more of the facial abnormalities associated with FAS. Individuals with pFAS have the same functional disabilities but may not have the physical appearance of an individual with FAS (5).

Alcohol-Related Neurodevelopmental Disorder (ARND) requires evidence of both prenatal alcohol exposure and CNS abnormalities, which may be structural or functional. Functional abnormalities may involve a complex pattern of cognitive or behavioral problems that are not consistent with developmental level and that cannot be explained by factors other than prenatal alcohol exposure (e.g., family background, environment, and other toxicities). Facial abnormalities and growth deficits need not be present (3). People with ARND might have intellectual disabilities and problems with behavior and learning. They might do poorly in school and have difficulties with math, memory, attention, judgment, and impulse control (1).

Alcohol-Related Birth Defects (ARBD) include problems with the heart, kidneys, bones, or hearing. People with ARBDs might have a combination of these (1). ARBD is rarely seen alone but rather as a secondary disorder accompanying other FASD conditions (e.g., FAS and ARBD) (3).

Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) was first included as a recognized condition in the Diagnostic and Statistical Manual 5 of the American Psychiatric Association (APA) in 2013. ND-PAE requires evidence of both prenatal alcohol exposure and CNS involvement, as indicated by impairments in the following three areas: cognition, self-regulation, and adaptive functioning. A child or youth with ND-PAE will have problems in three areas: 1) thinking and memory, where the child may have trouble planning or may forget material he or she has already learned; 2) behavior problems, such as severe tantrums, mood issues (for example, irritability), and difficulty shifting attention from one task to another; and 3) trouble with day-to-day living, which can include problems with bathing, dressing for the weather, and playing with other children. In addition to the child having problems in these three areas, the mother of the child must have consumed more than minimal levels of alcohol during pregnancy. The APA defines minimal levels of alcohol as more than 13 alcoholic drinks per month of pregnancy (that is, any 30-day period of pregnancy) or more than 2 alcoholic drinks in one sitting. (1, 3)

Prenatal Alcohol Exposure (PAE) may be associated with altered acquisition and distribution of body mass with increasing age. In a study conducted by Werts and colleagues, the exploratory data suggested that children with PAE may be at risk for nutritional deficiencies, which are influenced by inappropriate food preferences, disordered eating patterns, medication use, and the stressful dynamics surrounding food preparation and mealtime. PAE may be associated with female obesity, constant snacking, lack of satiety, constipation, and low vitamin D status. The obesity/overweight incidence for the female subjects was 50% (a rate substantially greater than the U.S. average of 31.3%), while the obesity/overweight incidence for the males was well below the U.S. average. The sample size was too small to determine whether obesity rates significantly differed between the sexes. (6)

Fetal Alcohol Effects (FAE) was previously used to describe intellectual disabilities and problems with behavior and learning in a person whose mother consumed alcohol during pregnancy. In 1996, the Institute of Medicine (IOM) replaced FAE with the terms alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD). (1)

Growth and Development of Children with FASD

The estimated prevalence of FASD in populations of first-grade schoolchildren (~6.5-7.8 years old) is as high as 20-50 per 1,000 in the United States and some Western European countries. (7)

In a study conducted by Spohr and others, it was found that although the characteristic craniofacial malformations of FAS/FAE diminished over time, microcephaly, a poorly developed philtrum, a thin upper lip, and, to a lesser degree, short stature and underweight (in boys) persisted. In females, adult body weight increased. Although some catch-up growth occurred, a large proportion of the subjects had growth deficiency. (8)

Retrospective research demonstrated that children may be more affected by prenatal alcohol exposure based on the following variables regarding the mother (3, 4):

- Poor pre-pregnancy or prenatal nutrition
- Multiple pregnancies and births
- Lower-than-average pre-pregnancy or prenatal weight, height, and body mass index (BMI)
- Maternal smoking
- Maternal age (effect on child increases with mother’s age)
- Has family members or peers who drink heavily

One study indicated that, anecdotally, children with FASD are often "picky eaters", some have autistic-like taste and texture sensitivities, and many have behavioral challenges such as rigidity and oppositionality. Children with FASD had lower intakes of saturated fats, vitamin D, and calcium. They may not meet the recommended intakes for several nutrients and have a dietary pattern that could benefit from improving intakes of dairy products, green leafy vegetables, vegetable oils, nuts, eggs, and fish. Most (>50%) did not meet the Adequate Intake for fiber, n-3 fatty acids, vitamin K, or choline, or the Recommended Dietary Allowance for vitamin D, vitamin E, or calcium. (9)

Another study indicated that children with FASD were more likely to have a past diagnosis of underweight. Mean BMI was significantly reduced for males but not females. Abnormal eating patterns are common in children with FASD and may contribute to their delayed growth and nutritional inadequacies. Children with FASD were significantly more likely to experience delayed acquisition of age-appropriate eating skills, compared with controls. The median age for solid foods introduction was significantly older for children with FASD as was their age at self-feeding. (10)

Breastfeeding may prevent or improve neurodevelopmental disorders for children with FASD and has been shown to improve IQ (11, 12). Infants with facial abnormalities may have breastfeeding challenges such as difficulty with latch, sucking, or swallowing; and individualized breastfeeding support will likely be needed (13). (See risk #372 *Alcohol and Substance Use* for more information regarding breastfeeding and alcohol use.)

There is no cure for FASDs, but research shows that early intervention treatment services can improve a child's development. There are many types of treatment options, including medication to help with some symptoms, behavior and education therapy, parent training, and other alternative approaches. Certain protective factors can help reduce the effects of FASD and help people with these conditions reach their full potential. Protective factors include diagnosis before 6 years of age; loving, nurturing, and stable home environment during the school years; absence of violence; and involvement in special education and social services. (1)

Adults with FASD

FASDs last a lifetime. Research to date indicates that, compared to controls, adults with FASDs have increased behavioral problems; are perhaps less efficient and more distractible when completing tasks; have more difficulty with paying attention, learning, memory, planning, and analyzing social situations; and feel less confident that they have sufficient resources to cope with their environment. Adults with FASDs have a high rate of psychiatric and personality disorders, problems with drugs and alcohol, and difficulties with the law. They are also less likely to obtain a degree, have stable employment, and live independently. Young adults with PAE have increased risks for mental health problems and secondary disabilities, which impacts their ability to live independently. (1, 14)

Implications for WIC Nutrition Services

When speaking with a biological mother of a child with an FASD, the American Academy of Pediatrics recommends the following (15):

- Building a rapport with the mother and allow her to express her emotions and concerns related to her child's health and the demands of parenting a child with an FASD.
- Reaffirming the parent as a key part of the child's care team.

- Keeping all lines of communication and advocacy open as the child's care is coordinated through the medical home.
- Referring to the National Organization on Fetal Alcohol Syndrome's Circle of Hope Birth Mother's Network that can be contacted in person or online: https://www.nofas.org/circleofhope/.

WIC staff can assist parents/caregivers of infants and children with FASD by:

- Providing anthropometric monitoring to address underweight, delayed growth, nutritional inadequacies, or overweight issues and concerns.
- Providing individualized food packages tailored to meet the needs of participants.
- Providing nutrition information regarding how to improve the intake of dairy products, green leafy vegetables, vegetable oils, nuts, eggs and fish when appropriate as this may be beneficial (9).
- Providing nutrition guidance to help with making appropriate choices for healthy snacks and satiety.
- Providing suggestions for addressing age-appropriate feeding skills and behavioral and developmental issues associated with feeding.
- Encouraging physical activity as it improves glucose tolerance, muscle development, motor coordination, and may stimulate neurogenesis and synaptogenesis (10).
- Referring to their health care provider to discuss nutritional supplements and any growth and development concerns (3).
- Providing referrals to promote caregiver and infant/child feeding skills, including referrals to local home visiting programs, parenting programs, and early intervention services.
- Referring to their health care provider for breastfeeding support. These infants may need frequent growth monitoring and re-evaluation of their feeding capacity, so feeding plans will need to be adjusted accordingly. (13)

WIC staff can assist adult participants with FASD by (also see risk #902 *Woman or Infant/Child of Primary Caregiver with Limited Ability to Make Appropriate Feeding Decisions and/or Prepare Food*):

- Providing individualized nutrition education in an easy-to-understand format that is appropriate for the learning level of the participant/caregiver. Most education materials should be written for a 5th to 7th grade reading level. Be sensitive to the unique learning needs and style of the participant/caregiver, which may mean using food models, posters, and handouts.
- Providing referrals to promote parenting and infant/child feeding skills, including referrals to local home visiting programs, parenting programs, and early intervention services.
- Encouraging participants/caregivers to follow health care provider's plan of care. Coordinate with health care providers as needed.
- Providing individualized food packages, tailored to meet the needs of participants. Some adults with FASD with a limited ability to make appropriate feeding decisions/prepare food may be unable to prepare powder or concentrated infant formula. Thus, for the safety of the infant, State WIC Agencies may allow ready-to-feed (RTF) WIC formulas to be issued when it is determined that the caregiver may have difficulty correctly diluting powder or concentrated formulas. Please refer

to your State WIC Agency's specific policies regarding the issuance of RTF, as policies vary from state to state.

- Referring to their health care provider to discuss nutritional supplements for pregnant women (3).
- Referring to Substance Use and Prevention Manual: Screening, Education and Referral Resource Guide for Local WIC agencies. Available from: https://wicworks.fns.usda.gov/resources/wic-substance-use-prevention-guide.

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Additional References and Resources

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Clarification

Self-reporting of a diagnosis by a medical professional should not be confused with self-diagnosis, where a person simply claims to have or to have had a medical condition without any reference to professional diagnosis. A self-reported medical diagnosis ("My doctor says that I have/my son or daughter has…") should prompt the CPA to validate the presence of the condition by asking more pointed questions related to that diagnosis.