Fetal Alcohol Spectrum Disorder (FASD)

Health Watch Table

Tao, Temple, Casson and Kirkpatrick 2013

Overview: Fetal Alcohol Spectrum Disorder is an umbrella term for the range of effects that can occur in an individual exposed to alcohol in utero. These effects can include various physical, intellectual and neurobehavioral deficits that vary widely in severity. Fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD) are now used to refer to each of the four sub-categories subsumed under FASD.[1,2] Prenatal alcohol exposure does not always lead to FASD.

Prevalence: The reported incidence of full FAS currently ranges from 0.2 to 2.0 cases per 1,000 live births and up to 43 per 1,000 among "heavy" drinkers (different population surveyed or different methods used). The prevalence of FASD has been estimated to be at 9.1 per 1,000 live births in the United States.[3, 4]

Etiology: Prenatal alcohol exposure
The range of deficits in FASD is associated with many factors, including the amount, time and frequency of exposure, as well as the state of health/nutrition of the mother and the genetic makeup of the mother and the fetus. ***There is no time during pregnancy when it is shown to be safe for mothers to consume alcohol. While binge drinking is especially dangerous, no amount of alcohol has been shown to be safe for all women.***

1. Diagnosis

Considerations	Recommendations
Children: Diagnosis of FAS is based on a combination of: ▸ history of prenatal alcohol exposure; ▸ characteristic facial features (smooth philtrum, thin vermilion border of the upper lip and small palpebral fissures); ▸ perinatal growth deficit (<10th percentile for height or weight); ▸ central nervous system abnormalities, whether structural (microcephaly), neurologic (seizures, motor problems or soft neurologic findings), or neurobehavioral problems.[5] Manifestations of FASD may overlap with other disorders of environmental or genetic (e.g., 22q11 deletion syndrome) etiology. It is essential to rule out such differential diagnoses, especially in the absence of confirmed prenatal alcohol exposure.[1,6] Experts call for early diagnosis and intervention with families of alcohol-affected children to: ▸ promote their development; ▸ minimize the occurrence of secondary disabilities (see list below in "Adult Diagnosis – Recommendations"); ▸ identify and support previously unidentified siblings, and ▸ seek to prevent subsequent pregnancies affected by alcohol.[7]	▸ Specific diagnostic guidelines for FASD are reviewed at www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Fetal-Alcohol-Spectrum-Disorders.aspx. Accessed March 2025. ▸ Consider referral for assessment to an appropriate resource for your community, preferably a multidisciplinary FASD team. Consider consultation with a medical geneticist to rule out other conditions of environmental or genetic etiology.[1,6] Referral guidelines include: • known substantial prenatal alcohol exposure (maternal intake ≥7 drinks per week or ≥3 drinks on multiple occasions) • Or if there is unknown prenatal alcohol exposure, but ▪ caregiver or parental concern, or ▪ three facial features (as listed), or ▪ ≥1 facial feature plus height or weight deficit, or ▪ ≥1 facial feature plus central nervous system abnormalities[8,9] ▸ Consider consultation with a medical geneticist to rule out other conditions of environmental or genetic etiology.[1,6]

Considerations	Recommendations
Adults: Separate criteria for adults do not exist, but diagnosis is more challenging because: ▸ facial features in children with FAS may not persist into adulthood;[1] ▸ growth deficiency likely does not persist past 18 months;[10] ▸ motor problems seen at age 4 may not be seen by age 25;[10] ▸ cumulative environmental influences (e.g., traumatic brain injury, alcohol and drug abuse, mental health issues) may distort the evaluation of brain function. Most individuals with FASD have an 'invisible' disorder and <50% meet current definitions of developmental/ intellectual disability.[11] However, "The diagnosis can lead to a paradigm shift in attitude and perception towards the affected individual from one of a … difficult individual or sociopath to that of an individual who is neurologically impaired and who needs appropriate assistance with specific management and treatment".[11]	▸ In addition to the data required for diagnosis, consider assessment of adaptive functioning[12] and concerns that could be considered secondary to FAS: • mental health issues • disrupted school experience • trouble with the law, incarceration • inappropriate sexual behavior • alcohol and drug issues • problems with independent living • unemployment • parenting issues Individuals may exhibit depression, anxiety or psychosis, poor judgment, poor impulse control, sexual promiscuity and victimization, restlessness, poor problem-solving skills, resistance to change, difficulty forming meaningful relationships, gullibility, inability to understand or to conform to social norms.[11] ▸ Because a history of prenatal alcohol exposure may be difficult to obtain for adults, consider the possibility in persons who have experienced one or more of the following: • premature maternal death related to alcohol use • living with an alcoholic parent • abuse or neglect • involvement with child protective services agencies • a history of transient caregiving situations • foster or adoptive placements[13]

2. Cognitive Function/Communication

Considerations	Recommendations
Children: ▸ Intellectual ability may vary by individual from average IQ to severe intellectual disability. Diagnostic category does not necessarily predict cognitive level, (i.e., needs of FAS, pFAS and ARND can all be substantial).[14] ▸ Learning disabilities, language and communication disabilities are common.[1] ▸ Executive functioning skills are often a significant weakness. This can lead to problems with emotional regulation, impulse control, and deficits in planning, organization, and attention.[15, 16]	▸ Refer for comprehensive assessment of cognition, communication, sensory function, daily living skills and academic abilities in order to identify strengths and needs and to make a comprehensive support plan for families and schools.[17] Individualized management plan can be based on the results of comprehensive assessments to enhance strengths and provide support for needs. ▸ Monitor individual education plan, educational testing, balance of special education and general education setting, academic progress, behavioral differences, later vocational planning. ▸ Consider therapeutic programs based on needs identified by assessment, such as speech language therapy, and memory/attention remediation programs. ▸ Comprehensive assessments should always include measures of executive functioning, as this area is very important for the application of cognitive skills in everyday life (see Adaptive Daily Living skills below).

Considerations	Recommendations
Adults: ▸ Cognitive skills may increase further or decline during childhood and into adulthood.[11] ▸ Significant deficits in mathematical ability often persist into adulthood.[11, 18] ▸ It is common to face challenges in transition to adult care; there are often gaps in services from childhood to adulthood.[11]	▸ Refer for comprehensive assessment in late adolescence or early adulthood to establish cognitive level and to plan for future needs. ▸ Consider the need for assistance with financial management from family members, support staff, conservator or public guardian. ▸ Consider services provided by state Department of Intellectual and Developmental Disabilities or equivalent and/or adult mental health services.

3. Adaptive Daily Living Skills

Considerations	Recommendations
Children and Adults: ▸ Support and supervision from care providers or family members is necessary to help individuals make and follow through on treatment plans and appointments. ▸ Functional daily living skills are often significantly lower than cognitive skills. Individuals with relatively high IQ scores may still struggle with social skills, financial and time management, and organization of daily life.[11, 19] ▸ Structured activities and routines can help with organizational issues.	▸ Invite care providers or family members to appointments to help facilitate follow-through. ▸ Consider referral to vocational support services (e.g., job coaches, supported employment services) to help adults find and retain employment. ▸ Consider structured social skills training programs to improve skills. ▸ Refer to occupational therapy or behavior therapy for help with setting up schedules and environmental supports. Specific intervention strategies might include using visual schedules, memory aids, checklists, sensory-motor interventions.

4. Physical Health Issues[1]

Considerations	Recommendations
Children and Adults: ▸ Conductive and sensorineural hearing loss and vision abnormalities are common in FAS.[5] ▸ Dental problems, including malformations and caries, are common in FAS.[5] ▸ Neurological assessment is part of the diagnostic work-up. Typical and atypical seizures may be present.[12] ▸ Inappropriate sexual behavior may be more common than anticipated. ▸ "Virtually every malformation has been described in patients with FAS."[12] ▸ Growth deficiency is common. ▸ Learning difficulties, poor capacity for abstraction, deficits in higher- level receptive or expressive language, problems in memory, attention and judgment may compromise access to health care services.	▸ Screen for hearing and vision problems at time of diagnosis. Follow-up should be guided by clinical findings. ▸ Brain stem auditory evoked response and/or otoacoustic emission testing between 6 and 12 months may help in early identification of hearing loss. Follow up any abnormal neonatal hearing screens. ▸ Counsel referral for dental hygiene and prompt treatment of caries. ▸ Neurologic disorders may need periodic assessment. ▸ Take a sexual history and provide counseling regarding contraception and sexually transmitted infections. ▸ Be aware of the possibility of congenital abnormalities ▸ Measure growth parameters, ensure adequate nutrition and manage feeding difficulties.[12] ▸ Address other physical health concerns as in the general population, keeping in mind these needs may interfere with optimal health care.[12]

5. Mental Health and Behavioral Issues

Considerations	Recommendations
Children: ▸ Attention disorders (e.g., ADHD) occur in many cases.[20] ▸ Childhood trauma and attachment disorders are common. Many individuals experience multiple home/ foster home placements, neglect, and abuse.[18]	▸ Evaluate and refer for attention-related disorders. ▸ Structured environments and structured tasks used in the treatment of children with ADHD may also assist children with FASD. ▸ Consider stimulants for FASD as help in managing some symptoms.[21] ▸ Consider individual counseling and/or positive mentorship programs (e.g., Big Brothers or Sisters, community support programs).
Adults: ▸ Psychiatric disorders occur in a large percentage of cases. Mood, anxiety and conduct disorders are common.[22] ▸ Underlying neurological deficits can lead to increased emotional reactivity.[15] ▸ Adolescents and adults with FASD may have difficulty with cognitive-types of therapy, partly due to language processing difficulties.[11] ▸ Addiction problems are common. They can begin in teenage years and continue into adulthood.[13] ▸ Interactions with the justice system often occur.[13]	▸ Monitor for psychiatric disorders and refer to psychiatric /mental health services as needed. ▸ Refer to counseling and/or behavior management as needed. ▸ Provide or arrange medication management for known diagnosis and symptoms such as for depression, anxiety. ▸ Refer to social services for ongoing case management and support. ▸ Focus counseling on concrete suggestions around behavioral strategies with close supervision. ▸ Monitor for impulsivity, adult hyperactivity and depression with suicidal tendencies. ▸ Monitor for substance abuse and refer for treatment as necessary. Identify/ monitor women at risk for alcohol use during pregnancy. ▸ Refer to Mental Health Court Services or Victims Aid, if possible, to assist with court processes.

6. Sleep

Considerations	Recommendations
Children and Adults: ▸ Sleep disturbance is common with prenatal alcohol exposure, and medical problems related to obstructive sleep apnea may have been overlooked previously.[12] ▸ Sleep disturbances, including bedtime resistance, shortened sleep duration, increased sleep anxiety and night awakenings, are common.[23]	▸ Consider referral for sleep evaluation, if clinically indicated. ▸ Screen for sleep-related disorders and consider referral to sleep medicine professionals, occupational therapy or behavior therapy for environmental adaptations.

7. Sensory Issues

Considerations	Recommendations
Children and Adults: May have sensory processing (integration) disorder, "clumsiness", or mild neurological or sensorimotor abnormalities. They may present with difficulties in performing activities of daily living, extreme avoidance of activities and/or agitation.[24]	▸ Occupational therapy assessment using a variety of tools may identify particular needs. ▸ A sensory screening questionnaire completed by a caregiver may reveal problems in sensory processing, areas including visual, auditory, tactile, olfaction, gustatory, vestibular, and proprioception. ▸ Once sensory processing concerns are identified, a sensory integration therapy plan designed by an occupational therapist may help the person to use sensory information in meaningful and natural ways.

Professional Resources

- *FASD Screening Tool Kit* — Includes resources and screening tools for primary health care professionals. Information and copies of the entire Tool Kit: https://adai.uw.edu/fasdtoolkit/. Accessed March 2025.
- *FASD Toolkit* — *American Academy of Pediatrics*. AAP website: https://www.aap.org/en/patient-care/fetal-alcohol-spectrum-disorders/?srsltid=AfmBOorVu4bbuqLdYPCUIpvrE5piayk933oV7IC1ra33acWOko5KEODq. Accessed March 2025.

Caregiver Issues and Resources

- *Let's Talk FASD* — Caregiver guide with recommendations for both children and adults with FASD. https://www.von.ca/sites/default/files/files/_fasdtool_fullproof_final_1.pdf. Accessed March 2025.

Additional Websites of Interest

- FASD and Child Welfare Community of Practice — Network to inform policy makers, program developers and practitioners about the needs of children with FASD in the care of child welfare jurisdictions and agencies, as well as early intervention practices. https://canfasd.ca/. Accessed March 2025.
- Proof Alliance — Formerly the Minnesota Organization on Fetal Alcohol Syndrome. St. Paul, MN. Website offers information and resources to individuals, families and professionals regarding FASD. https://www.proofalliance.org/. Accessed March 2025.
- FASD United — Washington, D.C.; Organization empowers people with FASD to educate systems of care and the public and advocate for better policies. https://fasdunited.org/. Accessed in March 2025.
- NOFAS-UK — National Organization on Fetal Alcohol Syndrome. London, England; Devoted to preventing alcohol use during pregnancy and supporting individuals and families living with FASD. https://nationalfasd.org.uk/ Accessed March 2025.

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Modified with permission of Surrey Place Centre. This tool was reviewed and adapted for U.S. use by physicians on the Toolkit's Advisory Committee; for list, view here.

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