

Diagnostic Overview of FASDs: Recognition and Referral

1: Introduction

Instructions & Course Objectives

Audio Script

Welcome to the *Diagnostic Overview of FASDs: Recognition and Referral* course, provided as part of the Collaborative for Alcohol-Free Pregnancy: Partnering for Practice Change.

In this self-paced course, there are several ways to access the training materials.

You may select a specific chapter or chapter section by clicking on a title. You may view the course in its entirety by clicking the "play" button in the video window and then clicking "next" to proceed to the next video. Click "back" to view the previous video.

You may access more information by clicking on the links or resources in the "Know More" section. Let's try it out. Pause the video and click on the "Know More Example."

In addition to the "Know More" links and resources, a full-course download is available that contains all course content in this training.

The goal of the *Diagnostic Overview of FASDs: Recognition and Referral* course is to provide a broad foundation of knowledge about screening and assessing individuals for fetal alcohol spectrum disorders or FASDs. Healthcare professionals working in pediatric practices who complete this course will be better equipped to identify FASDs.

After completing this course, participants will be able to

- Discuss the importance of obtaining a history of prenatal alcohol exposure for every patient;
- Describe the range of neurodevelopmental and related behavioral effects of prenatal alcohol exposure seen in persons with FASDs;
- Describe physical characteristics associated with prenatal alcohol exposure; and
- Discuss the ways to reduce the stigma associated with assessing a patient for effects of prenatal alcohol exposure.

Know More

Know More Example

You have successfully opened a “Know More” pop-up for more information. You will see the “Know More” resources change to reflect the current video.

Resources

CDC Fetal Alcohol Spectrum Disorders (FASDs)

<http://www.cdc.gov/ncbddd/fasd/>

CDC FASD Training & Resources

www.cdc.gov/FASDtraining

FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice

<http://www.mpfasdpc.org/causes/competency-based-curriculum-development-guide/>

2: Relevance to Pediatric Practices

FASD Overview

Audio Script

Prenatal exposure to alcohol may result in developmental injury to the brain and other organs that can have lifelong effects. These effects include

- Growth deficits;
- Structural and functional central nervous system (or CNS) impairments;
- Dysmorphic facial features; and
- Other congenital anomalies.

Many people are surprised that the effects of prenatal exposure to alcohol are greater than those of other recreational drugs and teratogens. In fact, a 1996 Institute of Medicine (or IOM) report states: “Of all the substances of abuse, including cocaine, heroin, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus.”

These effects comprise a range of conditions known as fetal alcohol spectrum disorders or FASDs.

In the United States, FASD is an umbrella term that encompasses a number of specific diagnoses, each of which has its own diagnostic criteria. This graphic lists these diagnoses. Fetal alcohol syndrome, or FAS, is the diagnosis with which most people are familiar. Yet FAS, with both physical and

neurodevelopmental features, occurs in less than twenty percent of children with prenatal exposure to alcohol. Other diagnoses with only neurodevelopmental features, such as alcohol-related neurodevelopmental disorder (or ARND) or neurobehavioral disorder associated with prenatal alcohol exposure (or ND-PAE), occur much more frequently but are not as well known by clinicians or the public.

Note that in this course, any reference to “the diagnosis of FASDs” means the diagnosis of one of the range of conditions under the FASDs umbrella since FASD is not a diagnostic term.

There are several approaches to the diagnosis of FASDs. Each approach uses different sets of established guidelines, resulting in a range of potential diagnoses under the FASD umbrella. These approaches will be presented after a discussion of assessment domains.

Know More

FASD Spectrum

- **Fetal alcohol syndrome (FAS)** - This term is used when both physical and neurobehavioral features are present. It also is the disorder most people have heard about. Fetal death is the most extreme outcome from drinking alcohol during pregnancy. People with FAS might have distinctive facial features, growth problems, and central nervous system (CNS) problems. People with FAS can have problems with learning, memory, attention span, communication, vision, or hearing. They might have a mix of these problems. People with FAS often have a hard time in school and trouble getting along with others.
- **Partial fetal alcohol syndrome (Partial FAS)** - This condition involves prenatal alcohol exposure and includes some, but not all, of the characteristics of full FAS.
- **Alcohol-related birth defects (ARBD)** - People with ARBD might have problems with the heart, kidneys, or bones, or with hearing. They might have a combination of these.
- **Alcohol-related neurodevelopmental disorder (ARND)** - 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, and judgment, and poor impulse control.
- **Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)** - This condition includes evidence of both prenatal alcohol exposure and CNS involvement, as indicated by impairments in the following three areas: cognition, self-regulation, and adaptive functioning.

Resources

AAP FASD Toolkit

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/default.aspx>

CDC FASD Fact Sheet

http://www.cdc.gov/ncbddd/fasd/documents/fasd_english.pdf

Prevalence

Audio Script

Many clinicians are surprised to learn that FASDs are far more common than previously thought. Although currently there is no ongoing system to monitor the prevalence of FASDs across the United States, a recent study estimated that up to 2-5% of school-aged children might have FASDs.

Compared to other well-known birth defects and developmental disabilities, FAS and all other FASDs are significantly more prevalent.

In particular, the prevalence of FAS is similar to that of Down syndrome, orofacial clefts, and spina bifida combined. Further, if all FASDs were combined, the prevalence would be even higher, perhaps approaching some other more commonly recognized developmental disabilities.

Therefore, most pediatric clinicians can expect to encounter children with FASDs in their practice. The hope is that through improved identification and diagnosis, care of children with FASDs and their families can be improved.

Know More

Higher Prevalence Populations

Because substance abuse, particularly alcohol, is involved in 50 to 80 percent of child welfare cases, prenatal alcohol exposure is a significant issue for children in the foster care system. One study found the FAS prevalence estimate among children in foster care to be 15 per 1,000 children. These children are at very high risk of a missed diagnosis or misdiagnosis since many of the attention and behavioral issues associated with FASDs also are seen in children with early trauma. A study among children in a Midwestern child welfare agency found that over 80% of children ultimately diagnosed with FASDs initially received no diagnosis related to prenatal alcohol exposure or they received the wrong diagnosis within the spectrum.

Other studies have consistently noted the importance of socioeconomic factors, with higher prevalence among children in poverty. Importantly, racial differences have also been noted. However, when poverty is controlled for, those racial differences tend to disappear.

Cost of FASDs

FASDs have high economic and societal costs. Costs associated with drinking while pregnant in the United States are estimated at approximately \$5.5 billion annually. Pregnancy-related costs include increased healthcare costs for mother and baby. In addition, societal costs may also be increased, and include special education and mental health services. The lifetime cost for an infant with FAS is estimated at approximately \$2 million. Reported Medicaid costs incurred by children with FAS in 2011 were nine times higher than costs for children without FAS.

Individuals with FASDs and their families require lifetime support and care. Many individuals are at increased risk for mental health disorders, disrupted school and employment experiences, legal problems, challenges with living independently, and substance abuse disorders. Parents and family members of individuals with FASDs experience increased levels of stress, and they can benefit from increased support.

The impact of FASDs goes beyond just the individual affected.

Annual Costs of Risky Drinking

- Fire Losses: \$2.914B
- Fetal Alcohol Syndrome: \$5.241B
- Motor Vehicle Crashes: \$13.462B
- Criminal Justice: \$24.253B
- Health Care: \$28.379B
- Lost Productivity: \$179.085B

Sacks, J. J., Gonzales, K. R., Bouchery, E. E., Tomedi, L. E., & Brewer, R. D. (2015). 2010 National and state costs of excessive alcohol consumption. American Journal of Preventive Medicine, 49(5), e73-e79.

Fetal Development Chart

This fetal development chart shows vulnerability of the fetus to defects throughout pregnancy. Alcohol in the mother's blood passes to the baby through the umbilical cord. Drinking alcohol during pregnancy can cause miscarriage, stillbirth, and a range of lifelong physical, behavioral, and intellectual disabilities. You can view CDC's Fetal Development Chart here:

https://www.cdc.gov/ncbddd/fasd/documents/fasdbrochure_final.pdf

Additional References

Amendah, D., Grosse, S., & Bertrand, J. (2011). Medical expenditures of children in the United States with fetal alcohol syndrome. *Neurotoxicology and Teratology, 33(2), 322-324.*

Chasnoff, I. J., Wells, A. M., & King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics, 135(2), 264-270.*

O'Connor, M. J. & Whaley, S. E. (2003). Alcohol use in pregnant low-income women. *Journal of Studies on Alcohol, 64(6), 773-783.*

Sacks, J. J., Gonzales, K. R., Bouchery, E. E., Tomedi, L. E., & Brewer, R. D. (2015). 2010 National and state costs of excessive alcohol consumption. *American Journal of Preventive Medicine*, 49(5), e73-e79.

Resources

CDC Prevalence of FASDs

<http://www.cdc.gov/ncbddd/fasd/data.html>

CDC Vital Signs: Alcohol and Pregnancy

<https://www.cdc.gov/vitalsigns/fasd/index.html>

Evidence

Audio Script

The scientific basis for the adverse effects of prenatal alcohol exposure is well established, both by studies of humans and experimental research with animal models.

This image shows brain structures affected by in utero exposure to alcohol. The frontal lobe, cerebellum, and corpus callosum are areas most studied and consistently found to be affected. The frontal lobe and prefrontal cortex influence one's ability to plan, control impulses, and make good judgments, along with other executive functions.

The cerebellum affects motor functions, including equilibrium, as well as aspects of attention. The curved-shaped corpus callosum is the biggest white matter tract in the brain and known as the information superhighway passing impulses between the right and left hemispheres. The magnetic resonance images (or MRIs) depicted here show a child with no exposure on the left, compared to an individual with in utero exposure to alcohol on the right, showing the altered size and shape of the corpus callosum.

In addition, physiological changes in brain function have been documented by imaging studies. In particular, the movement of water molecules in the brain, as measured by diffusion tensor imaging, indicates increased diffusion of neuro-impulses. This results from less than optimal organization of white matter and impaired communication between brain structures.

These findings from studies with humans are strengthened by findings from mouse and rat models. This image shows an unexposed mouse on the left, compared to an exposed mouse on the right, showing the smooth philtrum, a cardinal dysmorphic feature indicating in utero exposure to alcohol.

Facial features form early in embryonic development and reflect underlying morphologic brain damage. Keep in mind that such damage can occur extremely early in gestation and before a woman might know that she is pregnant.

This growing body of research confirms alcohol's many roles in disrupting embryonic and fetal development of the central nervous system and other organs and structures.

Know More

Embryology

Animal studies have contributed substantially to our understanding of the embryological processes resulting in FASDs. In mice, during the equivalent of a human's first trimester exposure to alcohol, normal development of the neural tube and crest is modified, leading to microcephaly and the characteristic facial features of fetal alcohol syndrome.

During the equivalent of the second trimester, prenatal alcohol exposure affects the formation of radial glial cells resulting in abnormal neuronal migration.

During the equivalent of the third trimester, prenatal alcohol exposure can increase cell death and result in deficits in neuronal plasticity.

These studies confirm alcohol's many roles in disrupting embryonic and fetal development of the central nervous system and other organs and structures.

Additional References

Brocardo, P. S., Gil-Mohapel, J., Wortman, R., Noonan, A., McGinnis, E., Patten, A. R., & Christie, B. R. (2017). The effects of ethanol exposure during distinct periods of brain development on oxidative stress in the adult rat brain. *Alcoholism: Clinical and Experimental Research*, 41(1), 26-37.

Del Campo, M., & Jones, K. L. (2017). A review of the physical features of the fetal alcohol spectrum disorders. *European Journal of Medical Genetics*, 60(1), 55-64.

Ma, X., Coles, C. D., Lynch, M. E., LaConte, S. M., Zurkiya, O., Wang, D., & Xiaoping, H. (2005). Evaluation of corpus callosum anisotropy in young adults with fetal alcohol syndrome according to diffusion tensor imaging. *Alcoholism: Clinical and Experimental Research*, 29(7), 1214-1222.

Sulik, K. K., Johnston, M. D., & Webb, M. A. (1981). Fetal alcohol syndrome: Embryogenesis in a mouse model. *Science*, 214(4523), 936-938.

Wozniak, J. R., Mueller, B. A., Mattson, S. N., Coles, C. D., Kable, J. A., Jones, K. L., ... & Sowell, E. R. (2016). Functional connectivity abnormalities and associated cognitive deficits in fetal alcohol spectrum disorders (FASD). *Brain Imaging and Behavior*. 2016 Oct 12. [Epub ahead of print]

Resources

CDC FASD Competency-Based Curriculum Development Guide
https://www.cdc.gov/ncbddd/fasd/curriculum/fasdguide_web.pdf

Benefits of Diagnosis

Audio Script

We now turn to assessment and diagnostic issues.

Many clinicians wonder about the value and utility of making one of the FASD diagnoses, especially given the stigma associated with alcohol. We will return to the issue of stigma a little later, but research and clinical experience indicate there are significant benefits to making an FASD diagnosis, regardless of age of the affected individual.

While early identification and diagnosis allows for early intervention, and services are beneficial to any child with a disability, they are particularly helpful for children with FASDs. Research has shown that early diagnosis of an FASD is a protective factor against negative life events, such as school failure, trouble with the law, and homelessness.

A diagnosis can also help parents of children with developmental or behavioral problems “reframe” the child’s behavior to reflect his or her prenatal brain damage rather than lack of effort or willful disobedience—the “can’t” versus “won’t” misperception. Such reframing can greatly improve family functioning and educational efforts, as well as reduce stress or anxiety for the child, parents, and service providers. Finally, receiving a diagnosis can be a source of reassurance for parents of their parenting skills.

Appropriate diagnosis of an FASD also facilitates access to services and interventions. Early Intervention and Special Education services provide educational support for children with FASDs. These supports can be augmented with evidence-based interventions specifically adapted to the strengths and weaknesses of children with FASDs. The National Organization on Fetal Alcohol Syndrome (or NOFAS) clearinghouse includes links to services and resources and can be found in the “resource” section of this course.

An accurate and specific FASD diagnosis can guide functional assessments for educational and intervention purposes. It also helps avoid unnecessary or inappropriate testing, referrals, and interventions.

An additional benefit to diagnosis of a child is that it provides an opportunity to talk to the mother about preventing subsequent alcohol-exposed pregnancies, which could prevent FASDs among subsequent children.

Know More

Early Diagnosis

Individuals who are diagnosed with an FASD before 12 years of age are two to four times less likely than individuals diagnosed later to have adverse life outcomes, including

- Over two times less likely to have mental health problems;
- Over three times less likely to have disrupted schooling;
- Almost three times less likely to get into trouble with the law;
- Just over three times less likely to experience incarceration;
- Almost four times less likely to engage in inappropriate sexual behavior;
- Over four times less likely to have drug or alcohol problems;
- Just under two times less likely to be unemployed as an adult; and
- About four times more likely to be living independently as an adult.

Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. L. Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE): Final report. Seattle: University of Washington Publication Services. 1996.

Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. Developmental and Behavioral Pediatrics, 25(4), 228-238.

Resources

NOFAS Information and Resource Directory

<http://www.nofas.org/resources/>

3: How are FASDs Diagnosed?

Concerns that Trigger an FASD Assessment

Audio Script

Concerns that could lead to an assessment for an FASD include

- 1) A self-reported or family concern about possible FASD;
- 2) A sibling with an FASD;
- 3) A history of confirmed or suspected prenatal alcohol exposure;
- 4) Growth deficiency (at or below 10th percentile for head circumference, height, or weight at any time, including prenatally);
- 5) Developmental or behavioral issues, such as hyperactivity, developmental delays, learning or memory issues, impulsivity, and social immaturity; and
- 6) Dysmorphic facial features characteristic of prenatal alcohol exposure.

Other risk factors that could prompt consideration of prenatal alcohol exposure include

- Prenatal exposure to other drugs, such as tobacco, marijuana, cocaine, or methamphetamine;
- Adoption, particularly from a region where alcohol use is prevalent, such as Russia or Eastern Europe; and
- Involvement with the child welfare system since approximately two thirds of cases involve parental substance abuse.

Because FASDs are more prevalent than generally recognized, a low threshold for assessing children for these disorders is encouraged.

Know More

Interview with Mother about PAE

VIDEO: Interview with Mother about Prenatal Alcohol Exposure (UW-Madison PIC) -

<https://vimeo.com/251564530>

Guidance on FASD Assessment

The AAP FASD toolkit provides a flow diagram to provide guidance on assessment and referral of individuals who are suspected of having FASDs.

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/default.aspx>

Additional References

Goh, P. K., Doyle, L. R., Glass, L., Jones, K. L., Riley, E. P. Coles, C. D. & Mattson, S. N. (2016). A decision tree to identify children affected by prenatal alcohol exposure. *The Journal of Pediatrics*, 177, 121-127.

Resources

AAP Evaluating a Child for FASDs

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/Algorithm-for-Evaluation.aspx>

General Diagnostic Considerations

Audio Script

There is no single test that reliably identifies the effects of prenatal alcohol exposure. However, as originally described by Dr. Ken Jones and his colleagues in 1973, four criteria are universally recognized as needing to be assessed when considering an FASD diagnosis.

These are

- History of prenatal alcohol exposure;
- Growth restriction (as defined earlier);
- CNS abnormalities, including structural, neurological, or functional neurodevelopmental impairment; and
- Presence of specific physical features.

These physical and neurodevelopmental manifestations range from mild to severe, due to amount of prenatal alcohol exposure, timing and pattern of exposure, as well as genetics and postnatal experiences. Clinicians need to keep this variability in presentation in mind when deciding if an FASD evaluation is warranted.

Know More

Diagnostic Assessment

The initial diagnostic assessment may include the following:

- Comprehensive history
 - Review of birth and medical records
 - General functioning
 - Social functioning
 - Family structure, relationship, and dynamics
 - Socioeconomic and cultural background
 - Child & family strengths as well as family & community resources
- Clinical interview with parents/caregivers or other professionals
 - Source of information – consider extent to which such individuals might be able to provide reliable, accurate information about the affected individual
 - Elicit presenting concerns and reason for assessment
 - Past evaluations and interventions
 - Developmental or behavioral concerns/history
 - Educational concerns/history
 - Problems with memory
 - Impaired judgment and impulse control

- Motor problems (such as problems with balance, poor hand-eye coordination, difficulty writing/drawing, or decreased muscle tone)
- Assessment of prenatal alcohol exposure (PAE) and other substances
- Medical history
- Family medical and psychiatric history
- Examination for dysmorphic facial features associated with PAE:
 - Smooth philtrum (area between the upper lip and nose)
 - Short palpebral fissures
 - Thin upper lip/vermillion border
- Clinical interview with individual with prenatal alcohol exposure
- Behavioral observations
- Standardized neuropsychological or psychoeducational testing

Resources

CDC Fetal Development Chart

https://www.cdc.gov/ncbddd/fasd/documents/fasdbrochure_final.pdf

Dr. Kenneth Lyons Jones on the History of FAS/FASD

<https://www.youtube.com/watch?v=xOuEH05ooqs>

FASD Research Challenges and Opportunities

https://www.researchgate.net/publication/236196539_Fetal_Alcohol_Spectrum_Disorders_Research_Challenges_and_Opportunities

Inquiring About Prenatal Alcohol Exposure

Audio Script

In general, discussing alcohol consumption is difficult for many clinicians. However, documentation of prenatal alcohol exposure is important when considering an FASD diagnosis. In addition, this information also provides important background, in case developmental or behavioral issues arise in the future.

Speaking with a mother about alcohol use during pregnancy may be uncomfortable, but it is an important part of routine practice and necessary to fully assess a child.

The American Academy of Pediatrics' (or AAP's) Bright Futures guidelines for health supervision of infants, children and adolescents suggests that pediatric clinicians ask mothers three screening questions about alcohol use.

AAP recommends that these questions be asked at all prenatal visits, the earliest well child visit, new patient visits, and whenever a related concern is observed or raised.

Here are the questions:

First, how often do you drink beer, wine or liquor in your household?

Second, in the 3 months before you knew you were pregnant, how many times did you have 4 or more drinks in a day?

Third, during your pregnancy, how many times did you have 4 or more drinks in a day?

If the response to any of these screening questions indicates use of alcohol, additional questions about the amount, frequency and timing of alcohol use may be appropriate for diagnostic purposes.

The conversation about alcohol use can be aided by

- Introducing questions while asking about pregnancy history in the context of general nutrition and exposures, such as medications or environmental toxins;
- Using open-ended questions, such as “tell me about your alcohol use in the 3 months prior to finding out you were pregnant;”
- Acknowledging that alcohol use during pregnancy is common; and
- Screening every pediatric patient to get information about exposure before there are concerns about effects since this can greatly reduce stigma and defensiveness.

Know More

Interview with Mother about PAE

VIDEO: Interview with Mother about Prenatal Alcohol Exposure (UW-Madison PIC) - <https://vimeo.com/251564530>

Resources

AAP Bright Futures

<https://brightfutures.aap.org/Pages/default.aspx>

Structural & Functional Brain Abnormalities

Audio Script

Because in utero exposure to alcohol alters prenatal brain formation and development, assessment for CNS abnormalities is essential. Such abnormal brain development can present as structural, neurologic, or functional manifestations.

The most common structural manifestation is reduced head circumference, known as microcephaly. Microcephaly is a head circumference below the 3rd percentile for a child's age and sex. Although microcephaly clearly indicates brain impact, several diagnostic schemes indicate that even head circumference below the 10th percentile may be indicative of in utero exposure to alcohol. Also, if imaging studies are available, as noted previously, changes in major brain structures may be evident, such as in the corpus callosum, cerebellum, or frontal lobe.

Neurologic signs may include vision or hearing impairments as well as fine or gross motor impairments. Coordination and visual-motor integration difficulties are frequently observed for children with FASDs.

By far the most frequently observed CNS abnormality for individuals with FASDs is impaired functional neurodevelopment or neurobehavior. Because many factors influence neurodevelopment of a child with an FASD, functionally these children present as a very heterogeneous group. However, a 2011 consensus conference sponsored by the National Institutes of Health and the Centers for Disease Control and Prevention found that impairments tend to cluster into three areas:

- Neurocognitive impairment;
- Self-regulation issues; and
- Poor or delayed attainment of adaptive skills.

Neurocognitive impairments may include

- Global impairment;
- Executive dysfunction;
- Deficits in learning or memory; and
- Difficulty with visual-spatial reasoning or motor coordination.

An important point to keep in mind when assessing neurocognitive impairment for an FASD diagnosis is that less than half of the children will score in the significantly impaired range, which is two standard deviations below the mean on standardized tests. Most will score in low average to borderline ranges, with a few individuals scoring in the average to above average range but with particular functional problems.

Functional indicators of self-regulation issues include

- Poor self-regulation;
- Attention deficits;
- Sleep issues;
- Poor impulse control; and
- Trouble regulating behavior and mood.

These deficits frequently manifest in prolonged tantrums for toddlers or unexplained moodiness for older children.

Delayed or unacquired adaptive skills may occur in

- Communication;
- Daily living skills;
- Socialization; and
- Motor skills in younger children.

These delayed adaptive skills are often seen as a child with an FASD being immature or acting much younger than his or her age or peers. Further, the combination of communication deficits and socialization deficits makes it very difficult for the child with an FASD to establish and maintain friendships. Unfortunately, like many children with developmental delays, children with FASDs are very susceptible to bullying or manipulation.

Specific diagnostic schemes are available that further delineate each of the most frequently observed areas of CNS abnormalities.

Know More

Co-Occurring Conditions

A person with an FASD is also more likely to have co-occurring psychiatric, emotional, or behavioral problems. These problems are called secondary conditions. Children and adolescents with FASDs have a 95% chance of experiencing mental health issues at some point in their life.

These additional problems often create additional challenges for an individual with an FASD in learning independent living skills. Difficulties arise in

- Appropriately communicating wants and needs;
- Making and keeping healthy relationships with friends and family; and
- Maintaining stability in housing, employment, and relationships.

A diagnosis before the age of 12 reduces the risk of developing secondary conditions.

Additional References

American Psychiatric Association. *The Diagnostic and Statistical Manual of Mental Disorders*. (5th Ed.). American Psychiatric Association Publishing: Arlington, VA. 2013.

Coles, C. D., Gailey, A. R., Mulle, J. G., Kable, J. A., Lynch, M.E., & Jones, K. L. (2016). A comparison among 5 methods for the clinical diagnosis of fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 40(5), 1000-1009.

Cook, J. L., Green, C. R., & Canada Fetal Alcohol Spectrum Disorder Research Network. (2016). Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, 188(3), 191-197.

Hagan, J. F., Balachova, T., Bertrand, J., Chasnoff, I., Dang, E., Fernandez-Baca, D., ... & Zubler, J. (2016). Neurobehavioral disorder associated with prenatal alcohol exposure. *Pediatrics*, 138(4).

Hoyme, H. E., Kalberg, W. O., Elliott, A. J., Blankenship, J., Buckley, D., Marais, A. S., Manning, M. A., ... & May, P. A. (2016). Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics*, 138(2).

Kable, J. A., O'Connor, M. J., Olson, H. C., Paley, B., Mattson, S. N., Anderson, S. M., & Riley, E. P. (2016). Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE): Proposed DSM-5 diagnosis. *Child Psychiatry and Human Development*, 47(2), 335-346.

Resources

CDC Fetal Development Chart

https://www.cdc.gov/ncbddd/fasd/documents/fasdbrochure_final.pdf

CDC Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis

https://www.cdc.gov/ncbddd/fasd/documents/fas_guidelines_accessible.pdf

Diagnostic Guide for Fetal Alcohol Spectrum Disorders

<https://depts.washington.edu/fasdnpn/pdfs/guide2004.pdf>

Growth Restriction

Audio Script

Growth restriction may be observed pre-or postnatally. For most diagnostic schemes, growth is considered significantly restricted if a child is at or below the 10th percentile for either height or weight, based on the child's age and sex. Some children have prenatal growth restriction and they are born small for gestational age. A child who is small for gestational age may or may not continue to have growth problems. Other children may have birth weight and length within normal limits but later demonstrate growth restriction.

Know More

Growth Charts

- Use the World Health Organization (WHO) growth charts found here (https://www.cdc.gov/growthcharts/who_charts.htm#The%20WHO%20Growth%20Charts) to monitor growth for infants and children aged 0 to 2 years in the United States.
- Use the Centers for Disease Control and Prevention (CDC) growth charts found here (https://www.cdc.gov/growthcharts/clinical_charts.htm) to monitor growth for children aged 2 years and older in the United States.

Why use WHO growth standards for infants and children aged 0 to 2 years in the United States?

- The WHO standards establish growth of the breastfed infant as the norm for growth. Breastfeeding is the recommended standard for infant feeding. The WHO charts reflect growth patterns among children who were predominantly breastfed for at least 4 months and still breastfeeding at 12 months.
- The WHO standards provide a better description of physiological growth in infancy. Clinicians often use the CDC growth charts as standards on how young children should grow. However, the CDC growth charts are references; they identify how typical U.S. children grew during a specific time period. Typical growth patterns may not be ideal growth patterns. The WHO growth charts are standards; they identify how children should grow when provided optimal conditions.
- The WHO standards are based on a high-quality study designed explicitly for creating growth charts. The WHO standards were constructed using longitudinal length and weight data measured at frequent intervals. For CDC growth charts, weight data were not available between birth and 3 months of age, and the sample sizes were small for sex and age groups during the first 6 months of life.

Why use CDC growth charts for children 2 years and older in the United States?

- The CDC growth charts can be used continuously from ages 2 to 19 years. In contrast, the WHO growth charts only provide information on children up to 5 years of age.
- For children aged 2 to 5 years, similar methods were used to create CDC's growth charts and the WHO's growth charts.

Resources

WHO Growth Charts

https://www.cdc.gov/growthcharts/who_charts.htm#The%20WHO%20Growth%20Charts

CDC Growth Charts

https://www.cdc.gov/growthcharts/clinical_charts.htm

Dysmorphic Facial Features

Audio Script

Most children with FASDs will not exhibit the minor dysmorphic facial features indicative of in utero exposure to alcohol. However, three facial features are considered specific to such exposure and reflect prenatal brain injury. Identifying these provides increased confidence in the diagnosis.

The three cardinal features are

- 1) Short palpebral fissures (the eye openings in the horizontal plane);
- 2) A smooth philtrum (the ridge under the nose and above the lip); and
- 3) A thin upper lip (referred to as a thin vermilion border).

In most diagnostic schemes, presence of some or all of these features is required for a diagnosis of FAS or partial FAS. Persons with other FASDs typically do not have this constellation of dysmorphic facial features, but have other characteristics and/or history of prenatal alcohol exposure.

Know More

Diagnostic Exam for Dysmorphic Facial Features

Dysmorphic facial features are minor anomalies or variations in facial development. All persons have physical features that can be considered dysmorphic. However, when these features occur in certain patterns or groupings, they can be indicative of a particular syndrome caused by a genetic or chromosome alteration, or by prenatal exposure to a toxin, such as alcohol. A table of overlapping and differential diagnoses for each dysmorphic characteristic is available in the guidelines for FAS diagnosis published by the National Task Force on FAS/FAE in 2004.

National Task Force on FAS/FAE. Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis. Centers for Disease Control and Prevention: Atlanta. 2004.

https://www.cdc.gov/ncbddd/fasd/documents/fas_guidelines_accessible.pdf

[Note: diagnosis of FAS only, the term FAE is no longer used]

Other Dysmorphic Features

In addition to these three cardinal features, several other less specific dysmorphic features may or may not be evident in persons with FASDs, including epicanthal folds, “railroad track” ears due to a prominent ridge, clinodactyly, a “hockey stick” palmar crease, and low nasal bridge.

These features change over the life span due to increase/shifting pockets of fats, collagen loss, and maturing bone/skull structure. The dysmorphic features associated with prenatal alcohol exposure are most evident during the preschool to early school age period. Nevertheless, in many cases the three cardinal features persist into adulthood.

Partial FAS (pFAS)

In 2005, Hoyme and colleagues published a revision of the Institute of Medicine criteria that provided additional guidance for diagnosis of partial FAS. This diagnosis is most appropriate for patients who show several characteristics of FAS but do not meet full criteria for that diagnosis. A comorbid diagnosis of ND-PAE also may be appropriate. For more information see Hoyme, H. E., May, P. A., Kalberg, W. O., Kodituwakku, P., Gossage, J. P., Trujillo, P. M., ... & Robinson, L. K. (2005). A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: Clarification of the 1996 Institute of Medicine criteria. *Pediatrics*, 115(1), 39–47.

Additional Reference

Del Campo, M. & Jones, K. L. (2017). A review of the physical features of the fetal alcohol spectrum disorders. *European Journal of Medical Genetics*, 60(1), 55-64.

Resources

CDC Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis

https://www.cdc.gov/ncbddd/fasd/documents/fas_guidelines_accessible.pdf

Available Diagnostic Guidelines

Audio Script

Any specific FASD diagnosis will include a combination of physical, developmental, and prenatal history factors observed during assessment. Specific criteria must be met for the diagnosis of each FASD. Several guidelines are currently available that operationalize the criteria for a diagnosis under the FASD umbrella. They are presented in this table, and references are provided in the “Know More” section.

While there are a number of schemes available, as mentioned earlier, they all build on the four areas of assessment originally outlined by Dr. Jones and colleagues in 1973 as well as the IOM report of 1996. Each guideline is a valid diagnostic tool. Professionals have various reasons for choosing one over another. Choose a method you are comfortable or familiar with and that works well in your practice.

Schemes that assess several FASD diagnoses include the Hoyme, et al. guidelines, the 4-digit code from the University of Washington, and the Canadian FASD Research Network guidelines. The National Task Force guidelines are only for FAS and the DSM-5 scheme is only for ND-PAE.

Although all schemes build on the original description of FAS and the IOM report, some differ in both number or types of features required and cutoff points indicating impairment. A comparison of some of these schemes was conducted and published in 2016. Despite differences in specific criteria, this comparison yielded moderate to substantial agreement as to whether a child should have an FASD diagnosis, but only slight to moderate agreement for specific diagnoses. Agreement was stronger for

physical characteristics of growth and dysmorphia than CNS characteristics, most likely reflecting the rapidly evolving understanding of the FASD behavioral phenotype.

Know More

Additional References

American Psychiatric Association. *The Diagnostic and Statistical Manual of Mental Disorders*. (5th Ed.). American Psychiatric Association Publishing: Arlington, VA. 2013.

Coles, C. D., Gailey, A. R., Mulle, J. G., Kable, J. A., Lynch, M. E., & Jones, K. L. (2016). A comparison among 5 methods for the clinical diagnosis of fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 40(5), 1000-1009.

Cook, J. L., Green, C. R. & Canada Fetal Alcohol Spectrum Disorder Research Network. (2016). Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, 188(3), 191-197.

Hagan, J. F., Balachova, T., Bertrand, J., Chasnoff, I., Dang, E., Fernandez-Baca, D., ... & Zubler, J. (2016). Neurobehavioral disorder associated with prenatal alcohol exposure. *Pediatrics*, 138(4).

Hoyme, H. E., Kalberg, W. O., Elliott, A. J., Blankenship, J., Buckley, D., Marais, A. S., Manning, M. A. ... & May, P. A. (2016). *Pediatrics*, 138(2).

Kable, J. A., O'Connor, M. J., Olson, H. C., Paley, B., Mattson, S. N., Anderson, S. M., & Riley, E. P. (2016). Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE): Proposed DSM-5 diagnosis. *Child Psychiatry and Human Development*, 47(2), 335-346.

Resources

CDC Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis
https://www.cdc.gov/ncbddd/fasd/documents/fas_guidelines_accessible.pdf

4: Challenges and Solutions

Challenges with Diagnosing Children with FASDs

Audio Script

There are distinct challenges associated with the FASD diagnosis. The most often cited challenge is obtaining an accurate and reliable history of alcohol use during the pregnancy.

Incorporating such history into routine care can reduce the awkwardness of discussing the topic. Asking routinely allows the clinician to develop a style and approach that is sensitive, yet effective, in eliciting the information. Also, it should be noted that in several diagnostic schemes, confirming prenatal alcohol exposure is not essential to make a diagnosis of FAS or partial FAS, if a sufficient number of diagnostic criteria are present.

It can be difficult to distinguish FASDs from some developmental or genetic disorders.

Having an FASD does not prevent an individual from having other behavioral and genetic conditions, which can overlap with an FASD in various ways. In general, if an individual has characteristics that are not typical of an FASD, it is important to consider other diagnoses and rule them out before assigning a diagnosis of an FASD or including it as a comorbid diagnosis. Examples of conditions with overlapping behavioral characteristics include conduct disorder, oppositional defiant disorder, mild intellectual disability, autism spectrum disorder, fragile X syndrome, and attention-deficit/hyperactivity disorder. Other genetic syndromes, such as the 22q11.2 deletion syndrome also known as DiGeorge syndrome, and other teratogenic exposures, such as toluene, Dilantin and their derivatives, can also result in similar dysmorphic features.

It is especially helpful to be mindful of how many of the key diagnostic features of FASDs change with age and with environmental influences. For instance, the overall facial appearance of individuals with FAS may change with age; however, in many cases evidence of the three cardinal facial features persists. Likewise, neurobehavioral characteristics will present differently depending on the child's age. For example, self-regulation impairment may present as sleep problems in infancy, prolonged tantrums in the preschooler, attention problems for the school-age child, and impulsivity in the adolescent or young adult.

One additional challenge that clinicians report is concerns about federal and state laws for reporting to child welfare agencies. The American Academy of Pediatrics provides the following guidance in their FASD Toolkit: "The Child Abuse Prevention and Treatment Act (also known as CAPTA) does not require clinicians to report to Child Protective Services if a child has been prenatally exposed to alcohol. Referral to Child Protective Services is required if the child has been diagnosed with an FASD in the period between birth and three years. The intent of this referral is to develop safe care and possible treatment plans if needed, not to initiate punitive actions."

Know More

Summary

Challenges with diagnosing an FASD include the following:

- Can be difficult to distinguish FASD from other developmental disorders

- Obtaining an accurate and reliable history of alcohol use during the pregnancy can be difficult and should be done as sensitively as possible; however, confirming prenatal alcohol exposure is not essential to make a diagnosis of FAS or pFAS
- Many of the key diagnostic features of FASD change with age and with environmental influences
- The overall facial appearance of individuals with FAS or pFAS may change with age; however in many cases the three cardinal facial features persist
- Resistance to receiving a diagnosis due to stigma and bias towards individuals living with an FASD

Resources

AAP FASD Toolkit

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/default.aspx>

American Bar Association:

<https://apps.americanbar.org/litigation/committees/childrights/content/articles/010311-capta-reauthorization.html>

CAPTA: A Legislative History

<https://www.childwelfare.gov/pubPDFs/about.pdf>

CAPTA: Public Law 114-98, the Comprehensive Addiction and Recovery Act (CARA) of 2016

<https://www.acf.hhs.gov/sites/default/files/cb/im1605.pdf>

Early Identification: Referral Requirements under CAPTA and IDEA

<http://ectacenter.org/topics/earlyid/capta.asp>

Stigma and Bias

Audio Script

One of the biggest challenges clinicians mention for identifying and appropriately diagnosing children with FASDs is the stigma associated with a mother who consumes alcohol during pregnancy or a child with such a diagnosis.

Stigma is behavior, such as labeling or differential treatment, against the individual or group. An important first step in addressing stigma is the recognition that it can originate from the clinician him/herself and can be communicated to the patient and his or her family by words and actions.

There are several steps clinicians can take to minimize stigma.

A first step is recognizing that stigma is not a characteristic of a birth mother or child with an FASD. Stigma is something that is placed upon the mother or child by the attitude and behavior of the clinician. Keep in mind that roughly 50% of pregnancies are unplanned and often women drink before recognizing they are pregnant. We know that there are mixed messages in the popular media about the risks of alcohol use during pregnancy. Also, individuals who have an alcohol use disorder or are dependent on alcohol often do not have control over their alcohol consumption. Therefore, the concept of blame is really not appropriate. Many birth mothers express sentiments such as, “I didn’t drink to purposely harm my baby.” It is useful to identify the common ground that most clinicians and mothers share, which is the best interest of the child. It can be helpful to tell a mother that this is not about blame, but to find the best way to help both the mother and the child.

Another form of stigma is thinking that there are no interventions or treatments that can ameliorate the adverse effects of prenatal exposure to alcohol. That these children are “unfixable” is a serious misconception. There are many evidenced-based, practice-informed, and promising approaches that can greatly benefit children with FASDs. Information about some of these interventions and treatments are available through the AAP FASD toolkit and the National Organization on FAS website.

Many clinicians believe that there may be resistance by a family to receiving an FASD diagnosis. This is another misconception. Although some families may have difficulty, many families find relief in a brain-based explanation for their child’s difficulties. The diagnosis provides families with context for their child’s behaviors and difficulties. It also gives reassurance concerning their parenting and allows for reframing the family dynamic to improve family functioning.

Finally, it is important to always use non-stigmatizing language. For example, instead of labeling a child “a FASD kid” the clinician should take care to say “a child with prenatal or in utero exposure to alcohol.” For mothers, the clinician can say “your baby was exposed to alcohol before birth” rather than “because you drank.”

A related concept to stigma that presents a challenge to identification and diagnosis is bias. Bias results from misperceptions about certain groups being more or less likely to be exposed to alcohol prenatally. Media has tended to focus on alcohol and substance abuse issues among American Indians, foreign adoptions, and those in poverty. This leads many clinicians to believe that they don’t see such patients, the “not in my practice” fallacy, resulting in a bias against considering FASD diagnoses. This bias can result in clinicians only asking certain families about alcohol use during pregnancy.

The reality is that all racial and socio-demographic groups are affected by prenatal exposure to alcohol. As indicated in Bright Futures, it is best to ask ALL families about prenatal alcohol exposure and to have it as part of routine practice. Further, given what is now known about the estimated prevalence of FASDs in the United States, almost all pediatric clinicians are likely to encounter children with FASDs.

Know More

Addressing Stigma and Bias

Stigma is a powerful, complex social and cognitive process that leads to discrediting, devaluing, or excluding a person or group of people based on a real or perceived difference.

The impact of stigma in health care is well documented and shown to be far-reaching. Stigma contributes to health disparities through its negative effect on individual health status and as a barrier to access and delivery of quality healthcare services.

Stigma is often associated with health conditions. Alcohol use disorders and substance use disorders are among the most stigmatized medical conditions.

The fear of judgment or perception of being devalued is one of the reasons that women may not disclose to healthcare professionals or others that they drank, or are drinking, during their pregnancy.

Resources

AAP Bright Futures

<https://brightfutures.aap.org/Pages/default.aspx>

AAP Toolkit

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/default.aspx>

NOFAS Resource Directory

<https://www.nofas.org/resource-directory/>

Interprofessional Referral for Diagnosis and Care

Audio Script

In many cases, it is not quite clear whether diagnostic criteria are met, so referral to a specialist is necessary. Who you refer to for a diagnostic evaluation and/or needed services will depend on the resources available in your area.

The optimal resource is a multidisciplinary clinic specializing in diagnosis of FASDs, but these are quite rare. There are many pediatric specialists who can be expected to be familiar with these diagnoses, including a geneticist or dysmorphologist, and a neurodevelopmental/behavioral pediatrician. When

considering a diagnosis of ARND or ND-PAE, specialists can include a neuropsychologist or behavioral psychologist.

As soon as an FASD diagnosis is suspected, referrals to determine the child's needs for education and behavioral management should be made. Even as the family is waiting to be seen for a diagnostic assessment, referrals to early intervention (for children age 3 years or younger), special education or specific therapies should be made.

Many times, an interprofessional approach is key to establishing a diagnosis.

Interprofessional collaborative practice is when healthcare professionals work in teams to optimize patient care. Team members make a deliberative effort to develop collaborative care plans. Team members work together and focus on the patient and family. This is especially important in working with families living with FASDs.

Know More

Core Competencies

There are four main core competencies to consider for interprofessional care:

- 1) Values and Ethics focuses on the importance and ethical obligation healthcare providers have to engage in team-based care
- 2) Roles and Responsibilities focuses on knowing the roles and scope of practice of each team member to allow each member to practice at the highest level of his or her licensure to address patient needs
- 3) Interprofessional Communication identifies the best practices needed for providers to communicate across the team, removing barriers like professional jargon
- 4) Team and Teamwork provides a basis for what facilitates good team function and how teams develop to become high performing

From these Core Competencies, disciplinary accrediting bodies have now created requirements for interprofessional education in health professions education. Your healthcare organization likely has its own approaches to this element of the Medicare Access & Chip Reauthorization Act, known as MACRA. To find out more, check with your healthcare system.

Resources

AAP Bright Futures

<https://brightfutures.aap.org/Pages/default.aspx>

AAP FASD Toolkit: Building Your Team

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/Building-Your-Team.aspx>

American Interprofessional Health Collaborative
<https://aihc-us.org/>

Catalyst Learning Center: Interprofessional Care for a Person with FASD Course
<http://catalystlearningcenter.com/courses/interprofessional-care-for-a-person-with-fasd/>

Interprofessional Education Collaborative
<https://ipecollaborative.org/>

MACRA Resource
<http://www.aafp.org/practice-management/payment/medicare-payment/faq.html>

National Center for Interprofessional Practice and Education
<https://campaignforaction.org/resource/national-center-interprofessional-practice-education/>

NOFAS Resource Directory
<https://www.nofas.org/resource-directory/>

5: Next Steps

What Should I Do Next?

Audio Script

The first step to FASD prevention, identification, and treatment is awareness of the issue. Learning about the prevalence, manifestations, and scope of FASDs, and best practices in assessment and management are key.

The Centers for Disease Control and Prevention, along with FASD Practice and Implementation Centers and National Partners, provide education, training, and tools for those who care for women at risk for an alcohol-exposed pregnancy and those who work with individuals living with FASDs.

Care for individuals with FASDs offers an ideal opportunity for interprofessional collaboration, as emphasized in the Medicare Access & Chip Reauthorization Act, known as MACRA, which took effect in 2017.

Visit 'cdc.gov/FASDtraining' for additional trainings and resources, and encourage other staff members to learn more about this issue.

In summary, there are several steps that healthcare professionals who serve pediatric patients can take to identify individuals with FASDs and refer them for treatment and services.

First, develop the practice of obtaining a history of prenatal alcohol exposure as a routine part of the history for all patients, according to the Bright Futures guidelines.

Second, know the behavioral and physical characteristics of FASDs as well as their presenting features.

Third, consider prenatal alcohol exposure in the assessment of children with behavioral and physical features.

Fourth, have referral information readily available for both medical specialists and intervention services.

Finally, follow AAP guidelines for care of individuals with FASDs.

You should now be able to

- Discuss the importance of obtaining a history of prenatal alcohol exposure for every patient;
- Describe the range of neurodevelopmental and related behavioral effects of prenatal alcohol exposure seen in persons with FASDs;
- Describe physical characteristics associated with prenatal alcohol exposure; and
- Discuss the ways to reduce the stigma associated with assessing a patient for effects of prenatal alcohol exposure.

Thank you for taking the Diagnostic Overview of FASDs: Recognition and Referral course.

Know More

Full Course Download

All topics and links that appear in the Know More section throughout this course can also be found in the "Full Course Download" document provided in the Resources section.

Resources

AAP Bright Futures

<https://brightfutures.aap.org/Pages/default.aspx>

AAP FASD Toolkit: Guidelines for Referral and Diagnosis

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/When-to-Refer.aspx>

CDC FASD Training & Resources
www.cdc.gov/FASDtraining

References

2: Relevance to Pediatric Practices

- Amendah, D., Grosse, S., & Bertrand, J. (2011). Medical expenditures of children in the United States with fetal alcohol syndrome. *Neurotoxicology and Teratology*, 33(2), 322-324.
- Brocardo, P.S., Gil-Mohapel, J., Wortman, R., Noonan, A., McGinnis, E., Patten, A. R., & Christie, B. R. (2017). The effects of ethanol exposure during distinct periods of brain development on oxidative stress in the adult rat brain. *Alcoholism: Clinical and Experimental Research*, 41(1), 26-37.
- Centers for Disease Control and Prevention. (2017). Fetal Alcohol Spectrum Disorders (FASDs): Data & Statistics. Retrieved from <https://www.cdc.gov/ncbddd/fasd/data.html>
- Centers for Disease Control and Prevention. (2014). Planning and Implementing Screening and Brief Intervention for Risky Alcohol Use: A Step-by-Step Guide for Primary Care Practices. Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities: Atlanta. Retrieved from <http://www.cdc.gov/ncbddd/fasd/documents/alcoholsbiimplementationguide.pdf>.
- Chasnoff, I.J., Wells, A.M., & King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, 135(2), 264-270.
- Del Campo, M., & Jones, K.L. (2017). A review of the physical features of the fetal alcohol spectrum disorders. *European Journal of Medical Genetics*, 60(1), 55-64.
- Institute of Medicine (1996). Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment. National Academy Press: Washington, DC.
- Ma, X., Coles C.D., Lynch M.E., La Conte, S.M., Zurkiya, O., Wang, D., & Xiaoping, H. (2005). Evaluation of corpus callosum anisotropy in young adults with fetal alcohol syndrome according to diffusion tensor imaging. *Alcoholism: Clinical and Experimental Research*, 29(7), 1214-1222.
- O'Connor, M. J., & Whaley, S.E. (2003). Alcohol use in pregnant low-income women. *Journal of Studies on Alcohol*, 64(6), 773-783.
- Sacks, J.J., Gonzales, K.R., Bouchery, E.E., Tomedi, L.E., & Brewer, R.D. (2015). 2010 National and state costs of excessive alcohol consumption. *American Journal of Preventive Medicine*, 49(5), e73-e79.
- Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. L. Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE): Final report. Seattle: University of Washington Publication Services. 1996.
- Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Developmental and Behavioral Pediatrics*, 25(4), 228-238.
- Sulik, K.K., Johnston, M.D., & Webb, M.A. (1981). Fetal alcohol syndrome: Embryogenesis in a mouse model. *Science*, 214(4523), 936-938.

Wozniak, J.R., Mueller, B.A., Mattson, S.N., Coles, C.D., Kable, J.A., Jones, K.L., ... & Sowell, E.R. (2016). Functional connectivity abnormalities and associated cognitive deficits in fetal alcohol Spectrum disorders. *Brain Imaging and Behavior*, [Epub ahead of print]

3: How are FASDs Diagnosed?

- American Academy of Pediatrics. (2017). Fetal Alcohol Spectrum Disorders Program: Flow Diagram for Evaluation. Retrieved from <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/Algorithm-for-Evaluation.aspx>.
- American Psychiatric Association. (2013). *The Diagnostic and Statistical Manual of Mental Disorders*. (5th Ed.). American Psychiatric Association Publishing: Arlington, VA.
- Astley, S.J. (2004). *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code-Third Edition*. University of Washington: Seattle. Retrieved from <https://depts.washington.edu/fasdnpn/pdfs/guide2004.pdf>
- Bertrand, J., Floyd, R.L., Weber, M.K., O'Connor, M.J., Riley, E.P., Johnson, K.A., & Cohen, D.E. (2004). *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis*. Centers for Disease Control and Prevention: Atlanta. Retrieved from http://www.cdc.gov/ncbddd/fasd/documents/FAS_guidelines_accessible.pdf.
- Coles, C.D., Gailey, A.R., Mulle, J.G., Kable, J.A., Lynch, M.E., & Jones, K.L. (2016). A comparison among 5 methods for the clinical diagnosis of fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 40(5), 1000-1009.
- Cook J.L., Green C.R. & Canada Fetal Alcohol Spectrum Disorder Research Network. (2016). Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, 188(3), 191-197.
- Del Campo, M., & Jones, K.L. (2017). A review of the physical features of the fetal alcohol spectrum disorders. *European Journal of Medical Genetics*, 60(1), 55-64.
- Goh, P.K., Doyle, L.R., Glass, L., Jones, K.L., Riley, E.P. Coles, C.D. & Mattson, S.N. (2016). A decision tree to identify children affected by prenatal alcohol exposure. *The Journal of Pediatrics*, 177, 121-127.
- Hagan, J.F. Jr, Balachova T., Bertrand J., Chasnoff I., Dang E., Fernandez-Baca D., ... & Zubler J. (2016). Neurobehavioral disorder associated with prenatal alcohol exposure. *Pediatrics*, 138(4).
- Hoyme, H. E., May, P. A., Kalberg, W. O., Koditwakku, P., Gossage, J. P., Trujillo, P. M., ... & Robinson, L. K. (2005). A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: Clarification of the 1996 Institute of Medicine criteria. *Pediatrics*, 115(1), 39–47.
- Hoyme, H.E., Kalberg, W.O., Elliott, A.J., Blankenship, J., Buckley, D., Marais, A.S., & May, P.A. (2016). Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics*, 138(2).
- Kable, J.A., O'Connor, M.J., Olson, H.C., Paley, B., Mattson, S.N., Anderson, S.M., & Riley, E.P. (2016). Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE): Proposed DSM-5 diagnosis. *Child Psychiatry and Human Development*, 47(2), 335-346.
- Warren, K., Hewitt, B., & Thomas, J. (2011). Fetal alcohol spectrum disorders research challenges and opportunities. *Alcohol Research & Health: The Journal of the National Institute on Alcohol Abuse and Alcoholism* 34(1), 4-14.

4: Challenges and Solutions

American Bar Association. (2011). The CAPTA Reauthorization Act of 2010: What Advocates Should Know. Retrieved from <https://apps.americanbar.org/litigation/committees/childrights/content/articles/010311-capta-reauthorization.html>