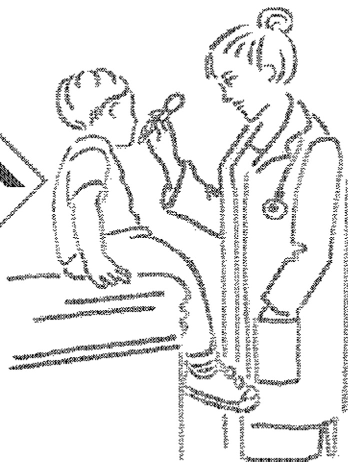
Understanding Fetal Alcohol Spectrum Disorders

Getting a Diagnosis



Jean is a recovering alcoholic. Her daughter has been to the hospital 10 times for heart and kidney problems. At 2, she can't walk or talk.

Katie is 5. She has no friends, throws tantrums, and can't read like other kids. Her teacher says she can't sit still or pay attention. Her birth mother drank on the weekends. Her adoptive mother is upset.

Dana is in substance abuse treatment. Her 13-year-old daughter has been suspended from school three times and has no friends. The school psychologist isn't sure what's wrong.

These children have baffling problems. Even a psychologist is stumped. Since the birth mothers drank alcohol, the children might have various types of fetal alcohol spectrum disorders (FASD).

WHAT YOU NEED TO KNOW

What Are Fetal Alcohol Spectrum Disorders?

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, behavioral, mental, and/or learning disabilities with possible lifelong implications. FASD is not a diagnostic term. It refers to several conditions.

The most well-known diagnosis is fetal alcohol syndrome (FAS). Signs of FAS include distinct facial features (smooth philtrum [groove between nose and upper lip], thin upper lip, small eye openings), growth deficiencies, and central nervous system (CNS) defects. The Institute of Medicine has identified three other diagnoses[1]:

- Partial FAS: facial anomalies and other symptoms without all the signs of FAS
- Alcohol-related neurodevelopmental disorder (ARND): CNS defects and behavior problems or cognitive deficits (e.g., speech delays, hyperactivity)
- Alcohol-related birth defects (ARBD): damage to organs, bones, or muscles

How Can I Recognize FASD?

Only trained professionals can make a diagnosis. Teachers or relatives may identify a problem, but they cannot diagnose an FASD.

Signs that may indicate the need for assessment include:

- Sleeping, breathing, or feeding problems
- Small head or facial or dental anomalies
- Heart defects or other organ dysfunction
- Deformities of joints, limbs, and fingers
- Slow physical growth before or after birth
- Vision or hearing problems
- Mental retardation or delayed development
- Behavior problems
- Maternal alcohol use

Why Is Diagnosis Important?

Because most people with FASD have no visible signs of alcohol exposure, their problems may be wrongly blamed on poor parenting or on other disorders. Early diagnosis and intervention contribute to positive long-term outcomes.[2] Accurate diagnosis can:

- Help the person receive appropriate services.
- Aid communication among clinicians, caregivers, educators, and families.
- Provide better self-awareness and understanding by family members.

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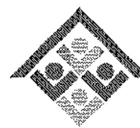

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How Is FASD Detected?

An expert trained to assess birth defects and FASD can make a diagnosis. Ideally, a team diagnoses the specific disorder. The team may include:

- Geneticist
- Developmental pediatrician
- Neurologist
- Dysmorphologist (physician specializing in birth defects)
- Education consultants
- Psychologists, psychiatrists, and social workers
- Occupational therapists
- Speech and language specialists

Tests usually include a complete physical (height, weight, vision, hearing, cardiogram, etc.), evaluation of the face, and an IQ test (e.g., WISC, WAIS). Occupational therapy, speech, neurologic, and psychiatric evaluations are used to check for:

- Cognitive deficits, such as memory problems, or developmental delay
- Executive functioning deficits, such as problems following multistep directions
- Motor delays or deficits, such as clumsiness or tremors
- Attention deficits and hyperactivity
- Poor social skills, such as interrupting others and misreading cues
- Behavior problems, such as aggression or not finishing tasks

Examples of specific tests clinicians use include Conners Rating Scales,[3] Vineland Adaptive Behavior Scales,[4] and Children's Memory Scale.[5]

Where Can I Go for a Diagnosis?

Depending on your community, you might go to a developmental pediatrician, an FASD clinic, a genetics clinic, or another specialist. The National Organization on Fetal Alcohol Syndrome (NOFAS) maintains a Web-based directory of FASD services at www.nofas.org/resource/directory.aspx.

How Do I Prepare for an Assessment?

It will help to record your child's history and behavior and make copies of any written reports. Bring the documents and photos of your child at various ages. Areas to note include:

- History of prenatal alcohol exposure
- Child's growth pattern
- Physical characteristics, such as atypical facial features
- Medical history, such as illnesses, surgeries, and vision or hearing problems
- Signs of CNS damage or behavior problems, such as memory problems or poor impulse control

What Do I Do With the Results?

Your child may be eligible for various services. A targeted treatment plan will help improve outcomes. Sharing the assessment results with your child's school can help in identifying appropriate services and teaching strategies. Your child might qualify for an individualized education plan, including services such as speech therapy and counseling.

You can also contact the department of social services or developmental disabilities services to ask what support is available. It might also be possible to obtain financial support, such as Supplemental Security Income. Finally, it is important to share the information with your child's pediatrician and other health care providers to help obtain appropriate medical and mental health services.

References

1. Stratton, K., Howe, C., & Battaglia, F. (Eds.). (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment.* Institute of Medicine, Washington, DC: National Academy Press.
2. Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. (1996). *Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE).* Final Report. Seattle, WA: Fetal Alcohol and Drug Unit, University of Washington School of Medicine.
3. Conners C.K. *Conners' Rating Scales—Revised.* North Tonawanda, NY: Multi-Health Systems.
4. Sparrows, S.S.; Balla, D.A.; and Cicchetti, D.V. *Vineland Adaptive Behavior Scales.* Circle Pines, MN: AGS Publishing.
5. Cohen, M. *Children's Memory Scale.* San Antonio: Harcourt Assessment.

If you're pregnant, don't drink. If you drink, don't get pregnant.

For more information, visit fascenter.samhsa.gov or call 866-STOPFAS.