

# ADDRESSING PARENTS/GUARDIANS OF CHILDREN DIAGNOSED WITH AN FASD: GUIDANCE FOR MEDICAL HOME PROVIDERS

Below are key elements that a medical home provider might want to address with parents/guardians.

Key Element/Message	Additional Details
Affirmation of a positive attribute or strength of the child	Developmental, physical, affect, appearance, well-loved, skills or interests, etc
Affirmation of a positive attribute of the parent or caregiver	Concern for child, nurturing, structure and discipline, advocacy, etc, and how that benefits the child despite difficulties posed by the acknowledged challenges
Restate the presenting concerns or questions to demonstrate understanding	The family may want to know about the FASD but want more help on the child's sleep issues.
Explanation of findings to support the diagnosis	
Discussion regarding the value of a diagnosis	<p>Not to blame but to better understand and help; availability of resources and interventions</p> <ol style="list-style-type: none"> <li>The diagnosis does not change who the child is, but should explain why the child develops, learns, and behaves the way she/he does.</li> <li>Most effective interventions for FASDs require understanding of the brain injury and will include changes in expectations and broad community support. Medication does not target the primary symptoms of most individuals with FASDs, although certain coexisting conditions may respond to pharmacotherapy (eg, anxiety and attention-deficit/hyperactivity disorder [ADHD]). In addition, traditional behavioral interventions may help to address the neurobehavioral issues related to FASDs. Parenting, educational, and counseling strategies have to be adjusted to support the needs of the child with an FASD.</li> <li>Discussion regarding resources that become accessible with a diagnosis (developmental intervention, educational services, behavioral support, parenting strategies, and medical referrals as needed).</li> </ol>
Discussion of resources provider can share/identify for action and support at the time of the visit	Referrals to an FASD clinic, referral to a clinic social worker for advocacy/parent support, referral to the school for educational/language evaluation or to developmental services, provision of educational materials for parent and, as needed, referral of family members struggling with alcohol use disorders, monitoring of neurodevelopmental status, and managing the child's special needs within the context of the medical home
Recognize that the impact of an FASD diagnosis will differ for a biological parent or close relative versus an unrelated foster or adoptive parent, and it is important to acknowledge the feelings associated with knowledge of the diagnosis.	Focus needs to be shifted from blaming the biological mother for drinking to understanding alcohol misuse, abuse, and alcoholism as a disease. In addition, attention needs to focus on determining the best course of treatment for a child who may have an FASD.
For a birth parent that is caring for the child, it is important to reaffirm that the parent has the best interest of the child at heart and is an important part of the care team.	It is important for the medical home provider to be able to discuss alcohol issues with a mother in a nonjudgmental manner. She may need reassurance as a parent and benefit from emotional support as well as professional and/or community referrals. She will also benefit from specific discussions regarding her child's diagnostic and treatment needs.
Emotional/physical trauma (eg, abuse) complicates the diagnoses and problem list and may require additional interventions.	Any mother who has concerns about her child should feel comfortable talking with her medical home provider, whether those concerns stem from prenatal alcohol exposure, environmental trauma, or other sources. It is important for the medical home provider to cultivate skills to be able to talk about these important issues.
It is important to recognize the role of the parent, whether biological, foster, or adoptive, as an integral part of the care team.	Children with an FASD often need an advocate or a champion, someone who can help explain the child's needs to her/his world and someone who can help explain the world to the child. The parents/caregivers may be this advocate but the parents/caregivers may also be empowered to seek out an advocate for the child in her/his school, in the mental health system, and in the community systems of support.

## Sample Script

---

It is good to see you and (*child's name*). (*Child's name*) is a very sweet/cooperative/(*other adjective*) child. You do a great job parenting/taking care of her/him. You appear to be concerned about fetal alcohol effects/fetal alcohol spectrum disorders/fetal alcohol syndrome given the history of prenatal alcohol exposure. Based on what we see today, (*child's name*) meets full criteria for fetal alcohol syndrome (mention facial, growth, and central nervous system features as needed or based on how conversation flows). The diagnosis helps guide everyone around (*child's name*), so that they know how best to help him/her. Based on our developmental screening, she/he is strong in \_\_\_\_\_ and \_\_\_\_\_ but delayed in \_\_\_\_\_.

It may be helpful to refer her/him to an FASD clinic/developmental-behavioral pediatric clinic to determine her/his developmental abilities in the various domains (eg, gross motor, fine motor, language, cognitive/IQ, educational). We could also make referrals to 0 to 3/school system/developmental therapists (based on age/needs). (If the child has focal findings on a neurologic examination, it may be helpful to refer to a neurologist.)

Here is some literature on FASDs. There are some parenting strategies that other parents have found helpful. There are educational strategies that can be helpful to (*child's name*). I can have you connect with our family advocate (or social worker) or give you some information about family supports. We will follow (*child's name*) and coordinate her/his care. Do you have any questions so far?

**If speaking to biological mother:** You made a very important decision for both your health and (*child's name*)'s health when you stopped drinking at \_\_\_ months (or when you found out you were pregnant). At this time, we want to just make sure to monitor (*child's name*) and ensure that her/his medical, developmental, and educational needs are met. Here is some literature on FASDs.

There is a group of birth mothers through the National Organization on Fetal Alcohol Syndrome (or NOFAS) that you may wish to contact. Here is some information on support groups. (If the mother is trying to seek help to stop drinking: If you wish, we can help connect you with neighborhood agencies that address this issue. Here is the contact number. Our family advocate can also help you contact these agencies if you wish to get you the help you need.)

This diagnosis is only one piece of (*child's name*)'s puzzle. She/he is a unique individual, and it is important that we figure out the best way forward for her/him and your family. There can be other factors including genes, early nutrition, and environment. We are happy you are trying to provide the best environment for (*child's name*). You have done a great job being her/his advocate. By getting her/him diagnosed and helped, you are giving (*child's name*) the best possible outcomes.

Children with FASDs and their families may need the following services/supports:

1. Developmental services (developmental interventionist, speech-language pathologist, occupational therapist, neuropsychological evaluation)
2. Educational services and supports, including an Individualized Education Program
3. Parent training/support program—give parent resources that are outlined in the toolkit (some of these are general and some may be state-specific). Generally, children with FASDs need a very structured environment in which parents/caregivers can provide supports for the neurobehavioral differences. Learning self-care skills may be hard and may require the parents/therapists to break down life skills into manageable steps, which will need to be learned through repetition and practice and often with visual aids/picture schedules. Teaching good behaviors requires gentle modeling, guidance, and redirection, in the background of realistic expectations. For\_\_\_\_\_, we need to adjust our expectations for her/his behavior/learning knowing that developmentally, she/he is more like a \_\_\_-year-old (developmental age) than a \_\_\_-year-old (chronological age). REMEMBER TO USE HER/HIS STRENGTHS TO HER/HIS ADVANTAGE IN ANY THERAPY PLAN.
4. FASD-specific interventions (evidence-based)
5. Medication management, as needed, for comorbid diagnoses, such as ADHD, anxiety disorder, etc
6. Medical issues—vision/hearing/other diagnostics/referrals (cardiology, neurology, as needed).

### Other Helpful Resources

1. Fetal Alcohol Syndrome Multimedia Guide—Professional FAQ: [http://fas.academicedge.com/pro\\_faq.html](http://fas.academicedge.com/pro_faq.html)
2. How to Talk to Your Child With FASD about FASD: <http://come-over.to/FAS/HowToTalkFASD.htm>