

Children's Mental Health Matters



Number 3, September 2012

Addressing the Challenge of Fetal Alcohol Spectrum Disorder

By Gordon R. Hodas, M.D.

While September 9, designated as Fetal Alcohol Spectrum Disorder (FASD) Awareness Day nationally and in Pennsylvania, has now passed, everyone familiar with this condition will agree that FASD awareness needs to be an ongoing process. Therefore, I want to discuss the challenge of FASD and offer some thoughts about how to address it.

FASD is the umbrella term given to all birth defects that result from a child's exposure to alcohol in utero. Fetal Alcohol Syndrome (FAS), one type of FASD, involves: a) specific facial features, in association with b) growth retardation, and c) neurobehavioral symptoms. FAS is most commonly diagnosed by a pediatrician or other primary care doctor. Individuals with partial FAS (with two of the above three components) may also be diagnosed in primary care, especially if the typical facial features are present. However, the vast majority of children with an FASD do not present with facial features. In addition the typical facial features with FAS may become less evident during adolescence, so that these children may also be overlooked. Many children who have been exposed to alcohol who have cognitive, emotional, and behavioral limitations and a history of psychosocial failure may not be recognized as having an FASD. For this reason, FASD is regarded as an invisible disability. As discussed in the [OMHSAS "Call to Action" white paper on FASD \(2011\)](#), when an FASD goes unrecognized, the child may be given inaccurate diagnoses and be subjected to inappropriate interventions that may at times cause adverse, secondary consequences.

In terms of the direct impact of alcohol use during pregnancy, there is no substance more toxic to a growing fetus than alcohol. Many women do not realize this, and many doctors do not provide the appropriate education to women of childbearing years.

For example, Kathleen Tavenner Mitchell, vice president and national spokesperson for the National Organization of Fetal Alcohol Syndrome (NOFAS), ironically describes how, years ago when she was addicted to drugs and alcohol, she intentionally abstained from all drugs and used only alcohol, thinking that this would benefit her child. Well-intentioned but significantly misinformed, Ms. Mitchell's gave birth to a child with significant symptoms of in utero alcohol exposure, namely FAS.

FASD can result in many negative, long term outcomes, referred as secondary effects. For example, many youth in inpatient units, residential treatment facilities, juvenile detention centers, and shelters have an unrecognized and unaddressed FASD. In addition, many homeless and incarcerated adults also have an FASD. FASD can be seen as both a personal tragedy and a public health concern. But mental health providers, educators, parents, and others cannot be expected to recognize a disorder with which they are unfamiliar.

FASD Awareness Goals

I believe that there is need for education of professionals, families, and youth in support of three broad awareness goals:

- Awareness that FASD is a totally preventable condition, when pregnant women abstain completely from using alcohol during their pregnancy.
- Awareness that FASD should be considered as a possible explanation for children of any age who under-perform academically; struggle behaviorally and emotionally, particularly with no apparent malice or intent to behave badly; exhibit impaired judgment; and fail to learn from experience.
- Awareness that the appropriate management and interventions for a child with an FASD are often quite different than those for a typical child or a

child with common behavioral health disorders. Due to impairments in comprehension, processing, and self-control, children with an FASD often do not respond to motivationally-based behavior plans and the use of rewards and consequences. Such children are then at risk of being labeled “resistant” and then scapegoated.

We need to recognize that the challenge posed by FASD is significant. It has been estimated that 1 in 100 hundred babies in the United States is born with an FASD, a number roughly equivalent to the estimated prevalence of children with an Autistic Spectrum Disorder. Moreover, many in the field believe that the actual incidence of an FASD in children is much greater than the identified 1 percent.

Other pertinent aspects of FASD are identified in Governor Tom Corbett’s 2012 Proclamation of FASD Awareness Month in Pennsylvania:

- FASD is the leading preventable cause of intellectual and developmental disabilities.
- An estimated \$6 billion is spent nationally to treat children and adults diagnosed with an FASD (and this does not include the cost for those with an FASD who have not been identified).
- One in eight pregnant women currently uses alcohol at some point during their pregnancy.
- More than 50 percent of women of childbearing age drink alcohol.

Given the significance of the challenge posed by prenatal drinking and its possible effects on children and on individuals over the lifespan, what can be done? In what follows, I offer recommendations, in turn, for individuals, for mental health and drug and alcohol professionals, and for behavioral health managed care organizations.

Recommendations for Individuals

- Learn about FASD, so that it can be as familiar to you as Autism and Attention Deficit Hyperactivity Disorder (ADHD).
- Read the OMHSAS “Call to Action” paper and check out various websites, including NOFAS (www.nofas.org).
- For women who are pregnant or trying to get pregnant, accept that avoidance of alcohol needs to be absolute. While the same injunction applies to the use of other substances as well, recognize that

alcohol is the most extreme toxin to the child’s brain.

- Educate all women of childbearing age about the risks of alcohol during pregnancy, including students in high school.
- Avoid the temptation to engage in all-or-nothing thinking regarding alcohol use. The impact of alcohol during pregnancy is cumulative. So the use of alcohol prior to one’s awareness of pregnancy should not lead a woman to decide that it is too late to stop drinking.
- Engage spouses and other partners in supporting a woman’s alcohol abstinence during pregnancy.

Recommendations for Mental Health and Drug and Alcohol Professionals

- Add FASD to the list of disorders to be considered when a child or adolescent presents with cognitive, emotional, and behavioral challenges, particularly when symptoms do not fit a usual pattern and past interventions have not been helpful.
- Screen for FASD, and develop the expertise to pursue both screening and assessment at both the agency and office-based levels.
- Learn how to support the child with an FASD and the family, and be familiar with community resources.
- Be respectful of the birth mother, and appreciate that such respect is essential for engagement and motivation.
- Ensure that expectations are developmentally appropriate for the child, and that they do not exceed the child’s capacity to fulfill. Interventions that best help the child with an FASD involve the triad of modeling, mentoring, and monitoring.

The above considerations are also relevant for teachers and school personnel, and for pediatricians and other physical health professionals.

Recommendations for Behavioral Health Managed Care Organizations

- Determine the current expertise, practices, and capacity of network providers regarding screening, assessment, and interventions for children with an FASD.
- Target provider training.
- Prioritize the expansion of provider capacity.
- Work collaboratively with the physical health plans.

- Encourage providers to work collaboratively with the child's primary care physician and medical home.
- Support FASD awareness by mental health providers in their work with other child-serving systems.

References

Bureau of Children's Behavioral Health Services, Office of Mental Health and Substance Abuse Services. (2011). A [Call to action: Fetal Alcohol Spectrum Disorders](#): Awareness, identification, and intervention for children in Pennsylvania. Harrisburg, PA.

[Governor's Proclamation of 2012 FASD Awareness Month](#) (DDAP News Release, "Women reminded of health risks associated with drinking alcohol during pregnancy").

[National Organization on Fetal Alcohol Syndrome](#) (NOFAS).

Gordon R. Hodas, M.D. is a child psychiatrist consultant for the Pennsylvania Office of Mental Health and Substance Abuse Services.