

Sobering Thoughts: Town Hall Meetings on Fetal Alcohol Spectrum Disorders

Prenatal exposure to alcohol is one of the leading causes of preventable birth defects and developmental disabilities. During the past 30 years, fetal alcohol spectrum disorders (FASD), including fetal alcohol syndrome, have gradually begun to attract attention. However, awareness and understanding of the disorders remain low, and people who are affected are seriously underserved.

The FASD Center for Excellence held a series of town hall meetings in 2002 and 2003 to gauge the issues surrounding FASD nationwide. On the basis of its findings, the center proposed a series of recommendations to begin to remedy some of the deficiencies that were identified. (*Am J Public Health*. 2006;96:2098–2101. doi:10.2105/AJPH.2005.062729)

“All birds have wings. But not all birds can fly.”

—*Parent of a child who has fetal alcohol syndrome*

ALTHOUGH THE EFFECTS OF prenatal exposure to alcohol have been studied since the 19th century, the issue has long remained poorly understood and largely overlooked. However, it raises significant concerns for public health. Prenatal exposure to alcohol affects an estimated 40 000 newborns annually.¹ It is one of the leading causes of preventable birth defects and developmental disabilities.

After decades of research and a great deal of discussion, in 2004 experts in the field issued a consensus definition for disorders associated with prenatal exposure to alcohol. The term *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 include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. FASD includes disorders such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder, and alcohol-related birth defects.

Behavioral or cognitive deficits associated with FASD include mental retardation, learning disabilities, hyperactivity, attention deficits, and problems with impulse control, social skills, language, and memory. People who have an FASD are vulnerable to numerous problems throughout their lifespan, such as failure in school, substance abuse, mental illness, and involvement in the criminal justice system. The national costs of FAS alone are up to \$6 billion per year, including direct costs to the health, social, and justice systems and indirect costs associated with mortality, morbidity, disability, and incarceration.² Because of data collection issues, calculating the entire cost of FASD to individuals, families, and society is difficult, but the cost is overwhelming.

AN EMERGING PUBLIC HEALTH ISSUE

Today, FASD is appropriately viewed as an emerging public health issue, one that may grow with improved diagnosis and surveillance. Recognizing that, Congress established the FASD Center for Excellence in 2001 as part of a federal effort to address

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FASD. The center is operated by the Substance Abuse and Mental Health Services Administration, which is part of the US Department of Health and Human Services. The center's mandates include studying interventions and strategies for people who have an FASD, identifying communities with exemplary systems of care for FASD, providing technical assistance and training to improve services, and developing techniques for FASD prevention. To help achieve its mandates, the center has sought input from FASD constituency groups through its Steering Committee and a series of town hall meetings.

In 2002 and 2003, the FASD Center for Excellence convened 15 town hall meetings with individuals who have an FASD, their families and caregivers, service providers, researchers, policymakers, and community leaders. The purposes of the meetings were to identify needs and share information about services that prevent and treat FASD. The meetings also were intended to raise awareness, facilitate coordination among service systems, and increase support for services at the state level.

To organize the town hall meetings, the center worked with the FAS Family Resource Institute, the Alaska Office of FAS, and the National Organization on Fetal Alcohol Syndrome. These advocacy organizations were well positioned to recruit participants through established networks of concerned families, professionals, and organizations, and through traditional social marketing efforts.

More than 800 people participated across the nation, with more than 500 providing testimony in Alaska, Arizona, California, Colorado, the District of Columbia, Florida, Illinois, Maryland, Michigan, Minnesota, Mississippi, New York, South Dakota, Texas, and Washington. Most of the testimony came from foster and adoptive parents of children who have an FASD and service system professionals (Table 1). Their perspectives may have differed from those of groups less represented at the meetings, such as birth parents, persons who have an FASD, and medical professionals. Efforts are under way by the FASD Center for Excellence and others, such as the Centers for Disease Control and Prevention (CDC), to cast a wide net for examining the issue of FASD from all sides. However, the center is confident in the overall validity of the town hall findings. For example, testimony about barriers to obtaining a diagnosis coincides with the known scarcity of professionals who are qualified to make a diagnosis.

Testimony at the town hall meetings focused overwhelmingly on the need for services that treat and prevent FASD. The gaps cut across multiple systems and areas, including health care, education, mental health care, substance abuse treatment, developmental disabilities services, social services, housing, income support, vocational rehabilitation, criminal justice, prevention systems, and adoption laws (Table 2). The issues described in the testimony were consistent geographically,

TABLE 1—Number of People Who Testified at Town Hall Meetings, by Group: 2002–2003

Category	Approximate No. of Testifiers
Parents and caregivers	216
Adoptive parents	160
Foster parents	19
Grandparents	14
Stepparents	6
Mothers in recovery	12
Birth mothers	5
Individuals who have an FASD	30
Professionals	140
Community leaders	20

Note. FASD = fetal alcohol spectrum disorders.

with no notable regional differences. The findings echoed the results of an environmental scan that the center conducted to identify FASD prevention and intervention programs, which revealed a severe shortage of services nationwide.

Each town hall meeting participant who wished to testify was given approximately 5 minutes to provide oral testimony, which was recorded on audiotape and, in some cases, videotape. Those who did not wish to testify onsite were invited to submit written testimony.

On the basis of meeting transcripts, tapes, and written testimony, reviewers noted the general tone of the meeting, the problems and needs that were discussed, and the suggestions and recommendations that were made. Reviewers developed codes for topical categories and subcategories, and they entered a summary of each piece of testimony into a database. To determine how many times an issue was mentioned, reviewers searched the testimony text for key words. Reviewers also

used the database to determine the number of persons who testified from particular groups (e.g., parents, professionals).

UNDERSTANDING THE PROBLEM

The concerns raised during the town hall meetings fell into several broad categories: lack of appropriate services for persons who have an FASD, both overall and specifically for adults; lack of access to existing services; lack of effective prevention strategies; and the need for investigation and disclosure of prenatal exposure to alcohol during adoption and foster care placement.

Overall Services

"I don't think my job should be an advocate. . . . My job is to be the Mommy."

—*Parent of a child who has an FASD*

The town hall meetings revealed a general lack of appropriate FASD-related services. Within the health care system, FASD is often misdiagnosed or inappropriately treated. Obtaining a diagnosis is extremely difficult because of inconsistent diagnostic criteria and terminology combined with a shortage of professionals who are qualified to make a diagnosis. Insufficient knowledge and training about FASD, particularly among pediatricians, social workers, psychologists, and psychiatrists, results in failure to provide necessary services or to make appropriate referrals.

Town hall participants also spoke out repeatedly about the need for respite. Parents and caregivers described the extreme demands of caring for individuals who have an FASD, the resultant toll on families, and the need for relief. However, close supervision is imperative because of behavioral

TABLE 2—Needs of Individuals, Families, and Communities, Cited in Town Hall Testimony, by Frequency: 2002–2003

Needs Cited in Town Hall Testimony	Approximate No. of Mentions
Appropriate services for individuals who have an FASD and their families overall in every system of care	100
Diagnostic services	75
Adequate training of all providers working with individuals who have an FASD	60
Job support and help managing money for persons who have an FASD	50
Effective prevention strategies	35
Community education about FASD, such as warning signs where alcohol is sold	30
Alcohol treatment for women	20
Recognition of FASD as a disability	20
Physicians' understanding of FASD and their role in prevention	15
Supportive housing options for adults who have an FASD	15
Psychiatric expertise on psychopharmacology for FASD	10
Financial assistance	10
Enactment and enforcement of investigation and disclosure laws on prenatal exposure to alcohol in adoption and foster care	10

Note. FASD = fetal alcohol spectrum disorders.

and safety issues, and affordable and appropriate respite care is almost nonexistent.

Finally, the testimony reflected great frustration with the school system, particularly special education, largely because of lack of awareness and understanding about FASD. Many people spoke of their struggles to educate teachers and school administrators about FASD and the negative impact on children of inappropriate educational interventions. Some parents had resorted to quitting their jobs and homeschooling their children, which further isolated their children and created a financial burden. Numerous testifiers portrayed a wrenching educational experience that was fraught with failure.

Services for Adults

"We provide supervised living arrangements for those who have sustained brain damage in accidents, but we cannot extend that understanding to someone who has sustained brain damage prior to birth."

—*Parent of an adult child who has an FASD*

FASD is often perceived as a children's health issue, but the deficits and functional impairments associated with the disorders last a lifetime. The town hall testimony described the challenges that people who have an FASD face during adulthood. Difficulties with behavior, social skills, impulsivity, and poor judgment translate into problems with life skills, such as maintaining a job and managing money.

A number of people called for recognition of FASD as a disability. Some adults who have an FASD can live independently with proper assistance, such as appropriate housing, vocational rehabilitation, and income support (e.g., Supplemental Security Income, Social Security Disability Insurance). However, services are scarce, and many adults who have an FASD are ineligible. Some have IQs that fall within the normal range, which disqualifies them in some states despite their impairment, and others lack a diagnosis. Many remain at home with their parents or caregivers in the absence of



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acceptable alternatives. Parents described their fears for their adult children's well-being after they die, highlighting the need for future planning.

Access to Available Services

In addition to expanded services that specifically address FASD, town hall participants asked for increased access to existing services, such as special education, income support, housing, vocational rehabilitation, and developmental disabilities services. Because of low awareness and recognition, people who have an FASD often are not referred to appropriate services or are rejected as ineligible. Those who lack the facial features or low IQ associated with FAS struggle with a hidden disorder. They often are perceived as "normal," although their neurological problems make them function at levels that are far below normal.

Effective Prevention Strategies

"Well, it's okay. My doctor said I could have a little drink. It will help me relax."

—A nurse relaying comments made by pregnant patients

The town hall participants called for effective prevention strategies, particularly in the areas of community education, health care, and substance abuse treatment. Strategies should include all women of childbearing age, including adolescents, because many are potentially at risk for an alcohol-exposed pregnancy. More than half of women of childbearing age drink alcohol, and more than half of all pregnancies are unplanned. Alcohol can cause damage to a fetus during early pregnancy, before a woman knows she is pregnant. Even 1 episode of binge drinking (4 or more drinks on 1 occasion) can harm a fetus.

Many physicians continue to counsel their pregnant patients

that it is acceptable to have an occasional drink, yet there is no known safe level of alcohol use during pregnancy. Additionally, some women take such vague advice as a medical green light to drink, leading them down a slippery slope toward heavier drinking. Physicians also fail to screen women who may be at risk and refer them to appropriate services. Their reasons include fear of stigmatizing patients or incurring litigation; lack of screening tools, time, and services; and personal discomfort discussing the issue with patients. Many physicians also have a poor understanding of FASD.^{3,4}

Pregnant women and women of childbearing age who are in treatment for substance abuse are at high risk for an alcohol-exposed pregnancy, but many may be in the dark about FASD. During a special town hall meeting for women in recovery, women testified that while in treatment, they had not been told about the dangers of drinking during pregnancy.

The Institute of Medicine classifies prevention programs as universal, selective, or indicated. For FASD, universal prevention includes educating the general public with tools such as alcohol warning labels. Selective prevention efforts target pregnant women or women of childbearing age, often through screening and intervention. Indicated prevention efforts address women at highest risk—such as women who have substance abuse problems or those who have given birth to a child who has an FASD—primarily through treatment. Research shows that selective and indicated prevention strategies can be effective in preventing FASD. Universal strategies help raise awareness but have not been shown to change behavior and prevent FASD.^{5,6}

The FASD Center for Excellence has identified and analyzed 639 prevention and intervention programs associated with FASD in the United States and Canada. Few of the programs specifically address FASD, and prevention programs are particularly scarce. It is difficult to discern best practices among the programs, because few have been evaluated to determine their effectiveness. No comprehensive systems of care for the prevention or treatment of FASD have been identified.

The National Registry of Effective Programs, which evaluates promising and best practices for substance abuse prevention and treatment, has approved 2 programs that help reduce rates of FASD. The Nurse–Family Partnership Program in Denver, Colorado, provides home visits by registered nurses to expectant and new mothers and is considered a model program. Although it does not specifically target FASD, the program has been shown to reduce substance use and improve birth outcomes. The Parent–Child Assistance Program in Seattle, Washington, has been recognized as a promising program. It also involves home visits to expectant mothers and has been shown to reduce alcohol use and improve birth outcomes.

Investigation and Disclosure Laws

"Social services denies that kids have problems related to FASD and hides information."

—Parent of a child who has an FASD

Many of the town hall attendees who testified were foster or adoptive parents of children who have an FASD. Typically, they had been unaware of their child's health status at the time of placement. In many cases, it took

years to unravel the mystery of their child's problems—years in which the children and their families suffered tremendously because of lack of a diagnosis and services. Many parents spoke of their grief upon learning that the adoption agency or social services knew about the birth mother's history of alcoholism. Often, children suffer further from the detrimental effects of multiple foster care placements, which may result in part from a poor understanding of the underlying cause of the children's behavioral problems.

Some states have disclosure laws that require agencies to inform foster or adoptive parents about a child's prenatal exposure to alcohol, but agencies often are unaware of exposure. Only a few states require agencies to investigate whether exposure occurred. Enactment and enforcement of investigation and disclosure laws are insufficient.

POLICY RECOMMENDATIONS

The town hall findings paint a vivid picture of the harsh realities that individuals who have an FASD and their families face in America. Meeting the critical needs that were revealed will require a concerted commitment by federal agencies, state governments, and private organizations. The following policy recommendations by the FASD Center for Excellence provide an opportunity for vital change in the prevention and treatment of FASD:

- Foster the development of evidence-based FASD prevention strategies by researchers and funding agencies.
- Ensure FASD training for professionals in various service systems, including health care, mental

health care, substance abuse treatment, education, social services, criminal justice, and prevention systems.

- Incorporate information on the prevention and treatment of FASD into the credentialing requirements for teachers, juvenile justice workers, lawmakers, and health care professionals as called for by the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect.⁷
- Develop a comprehensive system of care for FASD, with cost-effective prevention and treatment programs that increase awareness, build community support, foster legal and judicial reform, and improve diagnosis and services.
- Develop standard diagnostic criteria and terminology across the FASD spectrum and across the lifespan to increase the identification of FASD among all age groups and reduce confusion and misdiagnosis. The CDC recently released diagnostic guidelines that may aid this effort. Working with medical schools, the CDC also has established FAS regional training centers to develop and disseminate curricula on diagnosis and prevention for medical and allied health students and practitioners.³
- Ensure that all states adopt the federal definition of developmental disability, which does not set IQ limits. This shift will expand eligibility for benefits and services among individuals who have an FASD, thereby increasing their quality of life and decreasing their risk for poverty, unemployment, homelessness, and incarceration.
- Work with the American Psychiatric Association (APA) and the World Health Organization (WHO) to promote the inclusion of FASD in the APA's *Diagnostic and Statistical Manual of Mental Disorders* and the WHO's *International Classification of Diseases and Related Health Problems*. Inclusion of FASD in standard diagnostic manuals will increase awareness and knowledge among professionals and will support improvements in diagnosis.

Use the US Surgeon General's 2005 warning to develop a federal consensus statement about abstinence from alcohol during pregnancy, which will form the basis for clear, consistent prevention messages across all agencies that play a role in public health.

- Ensure the enactment and enforcement of state investigation and disclosure laws regarding prenatal exposure to alcohol.

CONCLUSION

The FASD Center for Excellence's town hall meetings made clear the nation's obligation to address FASD. Of primary concern are the need to close overall gaps in services, improve services for adults who have an FASD, improve access to existing services, implement effective prevention strategies, and enact and enforce state investigation and disclosure laws.

The federal government must improve FASD prevention and treatment by setting policies that will promote change and influence other entities that have a stake in the issue. By taking a leadership role, federal agencies can point the way toward a national strategy for improving the lives of people who have an FASD, preventing new cases of FASD, and reducing the considerable costs to society of prenatal exposure to alcohol. ■

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