

FASD Center News

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FIRST MAJOR MEETING OF THE FASD CENTER FOR EXCELLENCE HELD

The Agenda: Building FASD State Systems

Lifetime care for a person with FASD can cost over a million dollars, while preventing FASD can cost as little as \$5,000.

Preventing and treating fetal alcohol spectrum disorders (FASD) is a major challenge, especially without coordinated systems of care. To address this problem, the Substance Abuse and Mental Health Services Administration (SAMHSA) held the first-ever meeting on “Building FASD State Systems.”

Nearly 200 people attended the meeting in Arlington, Virginia, in May. Federal partners that participated include the Centers for Disease Control and Prevention, the Department of Justice, the Health Resources and Services Administration and the Center for Medicare and Medicaid Services. Sponsored by the SAMHSA FASD Center for Excellence and the National Institute on Alcohol Abuse and Alcoholism, the meeting brought together representatives of 49 States, the District of Columbia, and Puerto Rico. Staff from Federal agencies, nonprofits, and family groups also participated.

The meeting provided an unprecedented opportunity to network and share experiences in addressing FASD. Throughout the 3-day meeting, speakers and attendees raised several recurring themes:

- The need for resources for both prevention and treatment
- The lack of proper diagnosis and comprehensive services
- The need for collaboration across State agencies
- The need to inform the public that there is no safe level of alcohol use during pregnancy



Mikey Hoeven, first lady of North Dakota, was the meeting’s opening speaker. She spoke about her commitment to the health and future of the Nation’s children. Ms. Hoeven noted the importance of addressing FASD, because more than 40,000 babies are born each year prenatally exposed to alcohol. That number exceeds spina bifida, Down syndrome, and muscular dystrophy combined.

Many children with FASD grow up in multiple foster homes and never receive the diagnosis and services they so desperately need.

Instead, they face a lifetime filled with problems related to school, alcohol and drugs, behavioral and mental health issues, and crime.

Lifetime care for a person with FASD can cost over a million dollars, while alcohol treatment costs only \$5,000 to \$20,000 per individual. The first lady called on State governments to invest in FASD prevention and treatment, case management, improved diagnosis and services, and outreach to physicians.

**In This
Issue**

**Highlights
of the FASD
State Systems
Meeting**



ECONOMIC COSTS OF FASD ARE HIGH

FAS is enormously expensive. For individuals, lifetime costs average \$850,000 and may be as high as \$4.2 million.

Dr. Rick Harwood detailed the methodologies and results of various cost analyses. Cost estimates include factors such as health care, education, and residential expenses. As high as the costs are, Dr. Harwood said the estimates are conservative. For example, they focus on FAS and do not include other disorders in the spectrum. They also do not account for costs related to mental illness and criminal justice involvement. Given how much cheaper prevention programs tend to be than extensive services, the argument for prevention is quite compelling.

SPEAKERS STRESS PASSION, POLITICS AS TOOLS TO FIGHT FASD

Build a constituency and move forward. It takes a leader to do that. You are leaders.

Guest speaker Terry Lierman, a lifelong activist, spoke of the tremendous lost potential of children with FASD. He also noted his work with the National Organization on Fetal Alcohol Syndrome (NOFAS) and encouraged participants to take advantage of the resources NOFAS offers. He also urged them to be passionate about ending FASD, demand the resources they need, and build strong State constituencies. Tom Donaldson, executive director of NOFAS, echoed Mr. Lierman's call to build active constituencies to address FASD. He suggested partnering with individuals and families affected by FASD. Mr. Donaldson described them as heroes with compelling stories to tell.

FAMILIES DESCRIBE REALITY OF RAISING CHILDREN WITH FASD

FAS families dream of normal lives for their children.

Perhaps the most powerful session was one in which mothers described raising children with FASD. Teresa Kellerman, executive director of the FAS Community Resource Center, discussed life as the single parent of an adult son with FAS. In addition to physical problems such as a heart defect that required surgery, John had behavior issues. Other children did not want to play with him and babysitters were not an option. Unable to work due to John's needs, Ms. Kellerman cares for John and volunteers with the FAS Community Resource Center.

When Jocie DeVries' children were teenagers, she and her husband learned that her son has FAS and her daughter has FAE. Few services were available to help them. Determined to keep other families from facing FASD alone, they became advocates and helped found

the FAS Family Resource Institute.

Kathy Mitchell, program director of NOFAS and the birth mother of Karli Schridder, an adult child with FAS, also addressed the audience. She spoke of her experiences with alcohol addiction and

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Planning Committee Does Stellar Job

A caring and committed group of individuals from State agencies and private organizations helped plan the meeting. SAMHSA and the FASD Center for Excellence would like to acknowledge their efforts.

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* Unable to attend meeting

the effect it had on her children. Although two showed no effects, one died at birth and another died at 3 months. Karli spoke about how she is different from her siblings, who lead independent lives and are both married.

Ms. Mitchell said that her family has been affected tremendously by FAS but comes together as a team to provide Karli with a safe, happy environment. "Karli is a spiritual thread whose pure soul keeps us in check and keeps us connected and whole," said Ms. Mitchell. Ms. Mitchell and Karli served as a tangible illustration of the power of the stories of how FASD affects families.

The SAMHSA FASD Center for Excellence

The FASD Center for Excellence has six mandates from Congress:

1. Study innovative clinical interventions.
2. Identify exemplary community systems of care.
3. Provide technical assistance to communities.
4. Provide training on FASD.
5. Develop innovative prevention techniques.
6. Respond to recommendations by the National Task Force on FAS.

The Center conducts its activities in partnership with its Steering Committee, ICCFAS, the National Task Force on FAS/FAE, and SAMHSA grantees. The Center's goals are to advance the field of FASD and to facilitate the development of comprehensive systems of care. Activities include:

- Releasing a report on the 2002 Town Hall meetings and convening more meetings in 2003
- Operating an Information Resource Center, which is accessible by phone (866-STOP-FAS), mail, e-mail (fascenter@samhsa.gov), and Internet (www.fascenter.samhsa.gov/)
- Providing training and technical assistance to service providers, family members, government staff, community leaders, and others
- Piloting innovative interventions for individuals and families affected by FASD
- Compiling an extensive database of programs and publications related to FASD
- Convening the first-ever Women in Recovery summit and developing a birth mother network

REPRESENTATIVES FROM FASD STATE SYSTEMS DISCUSS CHALLENGES AND ACCOMPLISHMENTS

Representatives from FASD State systems shared their stories to help participants build or improve systems in their States. A number of common chords were struck regarding needs:

- Collaboration. The needs of individuals with FASD are so great, services so fragmented, and resources so scarce that joining forces within and across States is the only option.
- Community-based approaches. These are more effective than top-down programs and maximize resources.
- Sustainability and capacity building. Many States face slashed budgets and shifting political winds. Data are needed on the extent of FASD to support funding and programming.
- Prevention and treatment interventions for women at risk for alcohol-exposed pregnancies.
- Appropriate diagnosis and comprehensive, accessible services for persons with FASD.
- Increased awareness and education among the public and professionals, particularly physicians.



Examples of State and government efforts include:

- Alaska's Office of FAS, focusing on prevention, diagnosis, improved outcomes for individuals with FASD, and evaluation
- Minnesota's former ICCFAS
- Four-State FAS Consortium (North Dakota, South Dakota, Minnesota, and Montana), which works to build capacity and reduce risk factors for prenatal alcohol exposure

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- Canada's national advisory committee on FASD, which works across divisions of the health department and government
 - KIDS NOW (Kentucky Invests in Developing Success), an initiative to reduce the incidence and effects of perinatal substance abuse
 - Kansas's FAS State Coordinator working to enforce State laws to report cases of FAS and to make grant funds available for pilot programs to address FAS
- Colorado's statewide FAS prevention project housed in the Area Health Education Center

BREAKOUTS ZERO IN ON BARRIERS, SOLUTIONS, STRATEGIES FOR BUILDING FASD STATE SYSTEMS

The meeting was capped by five small discussion groups led by representatives who have had success in their States but also have faced their share of challenges. Session leaders spoke about effective strategies, common pitfalls, and surprise twists and turns that may occur on the road to building an FASD State system.

Attendees compared notes about each other's approaches to common challenges and left the sessions with ideas, contacts, and resources to guide them upon returning home.

Pam Gillen of Colorado led a discussion on meeting five particular challenges encountered in statewide prevention efforts:

- Rigid divisions between prevention and treatment budgets
- Data collection and reporting
- Limited travel budgets
- Sustainability
- Community readiness/planning grants

Participants conducted a SCOT analysis in a session led by Jane Stueve of Kansas and Dan Dubovsky of the FASD Center for Excellence. A SCOT analysis looks at strengths, challenges, opportunities, and threats involved in developing a statewide FASD system. Strengths included passion, common goals, Federal

and State recognition of FASD, and the investment and experience of parents of children with FASD.

Common challenges included funding, overburdened systems, poor attitudes, and lack of coordination at the Federal, State, and local levels. Opportunities included connecting with powerful individuals, accessing grants and foundation funding, and networking with other States. Threats included the possible loss of services due to legislative changes, as well as turf issues and shifting politics.

Strengths in developing FASD systems include passion, common goals, and the experience of parents of children with FASD.

Teresa Kellerman led a session on bridging the information gap. Participants identified information needs among FASD individuals and families, the system, and policymakers. They agreed that information from sources such as the March of Dimes and NOFAS can make a tremendous difference.

Key problems include lack of knowledge and training about FASD and available services, difficulty changing the system, and service eligibility barriers. Other major issues include chronic frustration among children with FASD and clinical depression, alcohol abuse, and behavior problems among adults with FASD. Ms. Kellerman brainstormed with the participants on potential solutions, including Federal and private resources, education, and respite care.

Diane Casto of Alaska led a discussion of the core components of an FASD State system. The group recognized that States face significant barriers, including lack of funding, data, and buy-in from providers. Ms. Casto emphasized the importance of finding a strong, committed FASD advocate to spearhead State efforts.

Other solutions that emerged included:

- Education
- Integration of FASD programming throughout State systems
- Community-based approaches

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- Capacity building
- Creativity and flexibility
- Alternative funding from sources such as alcohol trust funds

Jerome Romero, FAS State Coordinator for New Mexico, discussed creative funding efforts. He and the participants traded examples of collaborative strategies such as partnering with local radio stations to air public service announcements, working with organizations such as the Partnership for a Drug-Free America and the March of Dimes, pooling education funds with other groups, and using billboards and public transit to carry messages that raise awareness of FASD.

FASD CENTER FOR EXCELLENCE OFFERS TRAINING AND TECHNICAL ASSISTANCE

Want to know more about fetal alcohol spectrum disorders? Interested in issues such as loss and grieving, psychopharmacology, and criminal justice? Have no idea where to go? Try the FASD Center for Excellence.

Our staff have conducted more than 60 training sessions for nearly 3,000 people on various topics, including:

- FAS in the Criminal Justice System
- FAS 101
- Therapeutic Alliances
- Socialization Coaching
- Psychopharmacology
- Ethics and Boundaries
- Loss and Grieving
- Adolescents and Adults With FASD
- Co-Occurring Disorders
- FASD in Education
- Motivational Interviewing

We've also given presentations about the FASD Center to more than 600 people. Staff have trained in 18 States, the District of Columbia, and Canada.

Our staff also provide technical assistance, such as helping behavioral health systems develop FAS units,

researching literature and programs related to FASD, assisting in developing State plans for FASD, and providing case-specific support in addressing individual needs.

Want to know more? Contact our Information Resource Center at 866-STOP-FAS (786-7327), e-mail fascenter@samhsa.gov, or complete the Training/Technical Assistance Request Form on our Web site, <http://www.fascenter.samhsa.gov/misc/ttaintro.cfm>.



Upcoming Events

Prairie Northern Pacific FAS Conference: Our Communities Our Strengths, November 19-21, Winnipeg, Manitoba, Canada

For more information, contact Linda Storoschuk, 204-255-2244 or linda@plannersplus.ca, or visit www.fasconference.ca.

FASD 101, November 24-28, British Columbia, Canada

For more information, contact FAS/E Support Network of B.C., 604-576-9911, or e-mail info@fetalalcohol.com.

New Initiatives in Fetal Alcohol Spectrum Disorder for Native Americans, December 11-12, San Diego, California

For more information, contact Bill Zarchikoff, 888-683-7711 or 604-530-3840, or e-mail wzarchik@direct.ca.

Working with Adults with FASD, January 26-30, 2004, British Columbia, Canada

For more information, contact FAS/E Support Network of B.C., 604-576-9911, or e-mail info@fetalalcohol.com.

FAS Summit 2004: Sustaining Hope, Building Capacity, March 9-10, 2004, Anchorage, Alaska

For more information, contact Department of Health and Social Services, Office of Fetal Alcohol Syndrome, 877-393-2287.

Adults with FASD: Swimming Upstream: A Reality Check, March 24-26, 2004, Vancouver, British Columbia, Canada

For more information, contact Interprofessional Continuing Education, University of British Columbia, 604-822-4835.



IN OUR NEXT ISSUE

We'll highlight the first-ever Women in Recovery Summit in Baltimore, Maryland.

EDITORIAL GUIDE

We welcome your thoughts on newsletter topics and other issues. We'll publish letters to the editor with author's permission. E-mail fascenter@samhsa.gov and include "FASD Center News" in the subject line. Or write to FASD Center News, 1700 Research Boulevard, Suite 400, Rockville, MD 20850. Please include your name, city, and State.

Name Our Newsletter

We hope you enjoyed the premiere issue of *FASD Center News*. We invite entries for our Name Our Newsletter contest. E-mail fascenter@samhsa.gov with your entry. Include "FASD Center News" in the subject line. If you provide your name and permission, we'll print the winner in our next issue.



**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.



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
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