

FASD: Knot Alone

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Second Building FASD State Systems Meeting Brings New Faces and Issues

“Never give up hope.”

— Rep. Ken Svedjan, North Dakota

Rep. Ken Svedjan was one of many speakers at the second Building FASD State Systems meeting who spoke of successful efforts to recognize and address FASD. Held May 5-6 in Kissimmee, Florida, the meeting brought together many participants from last year’s successful BFSS meeting with a lot of new people who wanted to build momentum for State action. Representatives from all 50 States, the District of Columbia, and Puerto Rico gathered to learn more about FASD and to set goals and objectives for tackling FASD in their States.

Professionals from fields such as public health, mental health, substance abuse, and developmental disabilities joined individuals and families affected by FASD, Federal representatives, and others to map a better future. They were welcomed by Deborah Stone, Project Officer for the SAMHSA FASD Center for Excellence, and Ken DeCerchio, Director of Substance Abuse Programs, Florida Office of Drug Control, on behalf of the Governor.

Ohio First Lady Hope Taft delivered the keynote. Her pioneering work with several Ohio anti-drug initiatives introduced her to the tremendous personal and societal costs of FASD. Mrs. Taft cited statistics about the prevalence of FASD, which affects more children than spina bifida, Down syndrome, and muscular dystrophy combined. The lifetime cost for services for a child with an FASD is estimated at nearly \$3 million, a price borne primarily by taxpayers.

Mrs. Taft recognized the devastating effects of FASD on children and adults and stressed the need for more robust services for persons with FASD and their caregivers. She also emphasized the great need for prevention. Mrs. Taft endorsed a clear public health message for pregnant women: There is no safe amount of alcohol to consume and no safe time to drink.



Ohio First Lady Hope Taft

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In This Issue

Building FASD State Systems



States Reconnect and Recharge

A panel set the stage for discussing State systems by reviewing the components of an FASD comprehensive system of care. Issues included the system of care approach to service delivery, legal barriers at the Federal level, and New Jersey’s statewide screening and diagnostic program.

Attendees then formed State teams to develop 5-year goals and objectives and to identify barriers and strategies for success. Afterward, they convened in regional groups to compare notes and look for common ground. Finally, they reported their findings to the full group. Some common themes emerged, as shown in the table.

Goal	Number of States*
Develop a comprehensive State system (e.g., prevention, surveillance, diagnosis, services).	21
Increase training and education.	14
Collaborate with organizations, government agencies, and providers and build coalitions and task forces.	13
Increase knowledge and awareness of FASD.	12
Provide reliable diagnostic and screening services.	12
Increase the capacity of community-based services	10

*Includes District of Columbia and Puerto Rico; adds to more than 52 because some States had multiple goals.

In addition to the more common goals shown in the table, several States wanted to promote legislative efforts, increase communication about FASD, collect data (e.g., FASD prevalence), and unite stakeholders.

It was clear from the discussion of goals and ways to achieve them that States face many challenges. Representative Linda Lopez of Arizona and Representative Ken Svedjan of North Dakota discussed legislative challenges to addressing FASD. A key to promoting action is joining with other individuals and groups. Adam Litle, Director of Government Affairs for the National Organization on Fetal Alcohol Syndrome (NOFAS), described ways to build community coalitions to address FASD.

As shown by several States, the challenges are not insurmountable. Attendees from Texas, Ohio, Mississippi, and South Dakota shared how they had used what they learned at the first BFSS meeting to move forward with building a State system. Nadine Huggins, Manager, First Nations and Inuit Health Branch—FAS/E, Health Canada, provided an updated on Health Canada’s FASD activities.

Perspectives on Screening and Diagnosis Converge

Among the highlights of the BFSS meeting was a panel discussion about the evolving consensus on screening and diagnosis of FASD. Diagnostic criteria include facial characteristics, growth abnormality, central nervous system abnormality, and maternal alcohol exposure. These criteria are being established through various government, community, and research projects:

- The Centers for Disease Control and Prevention (CDC) National Task Force on Fetal Alcohol Syndrome/Fetal Alcohol Effects has established thresholds for four diagnostic components. The Task Force will release its diagnostic guidelines by August 2004, according to Louise Floyd, Team Leader of CDC’s FAS Prevention Office and an FASD Center Steering Committee member.
- Washington State developed the 4-Digit Diagnostic Code, which involves ranking four key features on a 4-point scale (see diagram). Susan Astley, Director of the University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network, said that the State has used the code to screen, diagnose, and intervene with high-risk populations.

	1	2	3	4
4				X
3			X	
2		X		
1	X			
	Growth	Face	Brain	Alcohol

Sample 4-Digit Diagnostic Code

- The Collaborative Initiative on FASD also has developed a diagnostic tool. Ed Riley, Professor, San Diego State University, and Co-Chair of the FASD Center Steering Committee, reviewed the initiative’s Dysmorphology Core Physical Examination Form

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and database. Clinicians can use the database to collect evidence of FAS and make a diagnosis.

- Larry Burd, Director of the North Dakota FAS Center and an FASD Center Steering Committee member, noted that screening identifies individuals who need further assessment. Because screening is not as precise as diagnosis, linkages to diagnostic clinics are essential. Dr. Burd emphasized the importance of FAS screening in collecting prevalence data.

FASD Is a Co-Occurring Disorder

“If we recognize FASD, we can improve treatment outcomes.”

—Dan Dubovsky, FASD Specialist

Individuals with FASD face an elevated risk of mental health and substance abuse disorders, due to genetic vulnerabilities and multiple stressors. Disorders that are likely to co-occur with FASD include attention deficit/hyperactivity disorder (ADHD), schizophrenia, depression, bipolar disorder, and anxiety disorder.



Dan Dubovsky

Dan Dubovsky, FASD Specialist with the FASD Center for Excellence, called for accurate diagnosis and treatment of co-occurring disorders in people with FASD. He described how cognitive impairments caused by FASD, such as problems following directions, can

hinder treatment. He also discussed the common problem of misdiagnosis.

People with FASD may be diagnosed with disorders such as ADHD, autism, oppositional defiant disorder, and conduct disorder, while FASD is missed. Symptoms of FASD can mimic those of other disorders, but the underlying cause and treatment approaches are quite different.

People with FASD who slip through the cracks face serious risks, ranging from inappropriate treatment to

unemployment, psychiatric hospitalization, homelessness, imprisonment, and death. A diagnosis can yield immeasurable benefits by replacing frustration with understanding and by putting individuals on the road to achieving the best possible outcomes.

Living With FASD: Individuals and Family Members Speak Out

Individuals and family members affected by FASD shared moving personal stories about dealing with FASD. The attendees applauded the courage of Erica, Betty, Ruth, and Rob, whose experiences crystallized the urgency of their own work. Erica and Rob are living with FASD, Betty is caring for an adult son with FAS, and Ruth is caring for her teenaged grandson with FAS.

Erica and Rob described their experiences with FASD. Erica said that school presented major challenges. Being diagnosed with an FASD was a relief because it helped explain her problems. Erica has completed 2 years of college but said, “Coping with FASD is a full-time job.”



Rob Wybrecht

Betty and Ruth face the daily pressures of caregiving in the world of FASD. Betty talked about her son’s behavior problems and substance abuse. A major problem has been getting an FAS diagnosis, which would help John get badly needed services. John is 44 and lives in an apartment above his family’s garage. He needs direction with everyday tasks and his parents’ worry about what will happen to John when they die.

In light of the difficulties families face, effective prevention and treatment are greatly needed. Several professionals described promising practices, including the Parent-Child Assistance Program (PCAP) Model, the FASD toolbox for educators, motivational interviewing, and Positive Behavioral Support.

State efforts to identify and implement promising practices, as well as their ongoing efforts, will help improve prevention and treatment of FASD. The

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dedicated participants at the BFSS meeting showed that with commitment and perseverance, there is hope for a better future for individuals and families affected by FASD.

Dan Dubovsky and Deb Evensen, FASD Specialists, teamed on a workshop on how to deal with the challenging behaviors of students with FASD.

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Alaska's Summit 2004: "Sustaining Hope, Building Capacity"

FASD Center staff once again showed a strong presence at the annual Alaska FASD Summit.

Nearly 800 professionals and laypeople attended the event, held in March in Anchorage. The summit was sponsored by the Alaska Office of Fetal Alcohol Syndrome.

Several representatives from the FASD Center for Excellence gave presentations. Project Officer Deborah Stone participated on a panel selected to help Alaska address unmet needs in the last year of Federal funding.

New Funds Available for FASD Projects

The Substance Abuse and Mental Health Services Administration has expanded the FASD Center's work to include coordinating subcontracts for planning and program development by States, community-based organizations, and criminal justice organizations. The Center will issue an RFP in the near future for these subcontracts.

Dear Dan



What part do men play in FASD? We have clients in treatment asking for more information on the role of the male.

Concerned Treatment Counselor

Dear Concerned:

I'm asked this question a lot. By definition, FASD cannot be caused by the father. The only cause of FASD is drinking alcohol during pregnancy.

Findings are mixed on the effects of alcohol use before conception. Some studies cite no discernible effects. Others show that sons of fathers who drank alcohol have increased levels of irritability and hyperactivity. There has also been some research that suggests that alcohol use can affect the motility of sperm. The only way to completely avoid risk is for both parents to be alcohol free prior to conceiving a child and for the mother to abstain completely throughout her pregnancy.

Men may not cause FASD, but they have a very important role to play in preventing FASD. They can encourage women not to drink during pregnancy. They also can support and respect a woman's decision not to drink. Men can also be role models for their



significant others. By not drinking themselves, they are modeling the safest behavior for pregnant women. Men can also help women get alcohol treatment and follow their treatment plans. These actions can help women remain alcohol free during their pregnancies.

Raising children with FASD can be very stressful. Often, the woman is the primary caregiver. Fathers can help ease the stress by providing support and sharing caregiving tasks.

As a treatment provider, you have a very important role in encouraging men to support their significant others in not drinking during pregnancy. You can also inform them that to be completely safe, they should not drink prior to conception.

I urge you to check the literature for more information. The FASD Center for Excellence has a searchable database on the Web at fascenter.samhsa.gov/search/index.cfm. Best wishes in your future work.

Have a question for Dan?

E-mail fascenter@samhsa.gov and include "Dear Dan" in the subject line. Letters may be edited for content and space. Please indicate whether you want your name and State published.



Upcoming Events

Get Ready for FASD Awareness Day!

International FASD Awareness Day, September 9, 2004, Worldwide

This is the sixth annual Awareness Day, where communities around the world organize events to promote awareness and reflection about the impact and implications of FASD for individuals, families, and society. Visit www.fasday.com or www.fasworld.com, e-mail fasworldcanada@rogers.com, or call (416) 465-7766.

Other Events

Hope for Women in Recovery summit and Birth Mothers Network meeting, June 29-30, 2004, Phoenix, Arizona

For more information, contact Brooke Tavenner, 202-785-4585 or tavenner@nofas.org, or Esther Roberts, 301-294-5607 or esther.roberts@ngc.com.

2nd NCBDDD Conference on Birth Defects, Developmental Disabilities, Human Development and Disability, July 25-29, 2004, Washington, DC

For more information, contact Janis Videtto, 770-488-7307, e-mail jfv1@cdc.gov, or visit www.cdc.gov/NCBDDD.

Conference by and for individuals with FAS/FAE, August 19-22, 2004, Camp Henry, Newaygo, Michigan

For more information, contact JoCindee Sawaquat, (231) 946-2370, or e-mail JCSurya@aol.com.

National Alcohol and Drug Addiction Recovery Month, September 2004, nationwide

For more information, contact the National Clearinghouse for Alcohol and Drug Information, 800-729-6686 or visit www.recoverymonth.gov.

Fetal Alcohol Spectrum Disorder 2004 Symposium, October 1-2, 2004, Pierre, South Dakota

For more information, contact the University of South Dakota, (605) 357-1431, 800-658-3080, or e-mail mnmiller@usd.edu.

On the Road Again: FASD Center Training Update

Business usually slows down during the cold winter months, but not for the FASD specialists. The FASD Center conducted nearly 30 training sessions for almost 1,500 participants in a variety of venues (see map for training locations), such as:

- FAScinating Families Camp, Alaska
- Navajo Nation, Arizona
- “Adults With FASD: Swimming Upstream—A Reality Check,” British Columbia, Canada
- Santa Clara Valley Hospital and Health Services Learning Institute, California
- Maternal and Child Health Conference, Washington, DC
- 14th Annual Delaware Prevention and Early Intervention Forum
- Indiana Association for the Education of Young Children Early Childhood Conference
- Mississippi FASD Symposium and Mississippi FASD
- Paterson School District, New Jersey
- Annual Indian School on Alcohol and Other Drug Related Issues, New Mexico
- Alcoholism and Substance Abuse Providers of New York State Conference

Training sessions addressed FASD through the lifespan; co-occurring disorders; FASD in education, families, substance abuse treatment programs, and the corrections system; ways to identify women at risk; and ways to work with “difficult” children and their families. Audiences included substance abuse and mental health professionals, social workers, policymakers, criminal justice personnel, educators, families, service providers, and Native American youth leaders and advisors.

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, fascenter.samhsa.gov/misc/ttaintro.cfm.





Ms. Evensen also gave a workshop on adapting curricula for students with FASD. She described how to design and implement developmentally appropriate instruction that can help prevent secondary disabilities such as academic failure. Mr. Dubovsky also led a session on the diagnosis and treatment of mental health disorders in individuals with FASD.

Candace Shelton, a Native American specialist, facilitated a roundtable discussion on FASD in Indian country. She described the findings of the FASD Center's site visits to 10 reservations and 5 urban Indian community health centers. The results illustrated the

need for a sustained, coordinated effort to develop FASD prevention and interventions in Indian communities.

Kathleen Tavenner Mitchell of NOFAS talked about the summit for women in recovery sponsored by the FASD Center and NOFAS. Ms. Mitchell noted that the summit helped build confidence among the women, with 91 percent feeling more hopeful about achieving recovery after the summit. In addition, nearly all the women left the summit with a much clearer understanding of how alcohol can affect the developing fetus. The Center has another summit planned for the summer and is supporting the development of a network for birth mothers of children with FASD.

Guest Editorial: I Didn't Know About FAS Until It Hit Home

Marceil Ten Eyck, M

As a member of the FASD Center for Excellence Steering Committee, I participate in many activities related to FASD. I've been to two Building FASD State Systems meetings, several Steering Committee meetings, and the first-ever summit for women in recovery. But the most challenging FASD-related activity I've been involved in has been raising two daughters with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE).

My older daughter, Sidney, was born 2-1/2 months early and weighed 2 pounds, 8 ounces. She spent several weeks in an intensive care nursery for premature infants. Her medical records included results of brain scans, many tests, procedures, and comments about my visits and phone calls to the nursery. The one thing that wasn't noted was my drinking. I was a middle-class professional with a successful career as an executive. Who would have asked if I had a drinking problem or drank while I was pregnant? In fact, my doctor had said that an occasional cocktail might be good for me.

When Sidney was 4, I was hospitalized with cirrhosis. I was supposed to die, but I think I chose not to. A year later I was treated for alcoholism and have been abstinent since. When I first heard about FAS, a cold, sick feeling lodged in the pit of my stomach. Sidney was 6 years old and small for her size. She had to

repeat kindergarten and had memory problems and an extremely short attention span. I figured the problems were due to her premature birth and the stress of my divorce.

Because of Sidney's ups and downs in school, a teacher friend suggested she be tested for learning disabilities. She was in 7th grade and had many difficulties. Her progress had been erratic, but she was denied testing because she was not 2 years behind. I wound up at the Pregnancy and Health Study Clinic at the University of Washington and with Dr. Sterling Clarren at Children's Hospital and Medical Center. When Sidney was diagnosed with FAS, I was horrified, but she was relieved. Finally, there was an explanation for her problems.

I spent some time in denial, convinced that she had been misdiagnosed. After all, she didn't look like a child with FAS. She was on the honor roll at school. She could play the piano. Still, I read everything I

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could find about FAS and tried to parent as if she had it. Sidney's tests at the University of Washington revealed her specific learning disabilities, which enabled me to work with her school counselor to develop an appropriate schedule.

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Like many teens, Sidney's adolescence was challenging, but FAS made it harder. She had poor judgment, no impulse control, and a need to fit in that made her fall prey to bad influences. She fell in with a gang, became sexually active, and did poorly in school. Her boyfriend was a constant source of trouble until I set him straight about the rules for dating Sidney. Ultimately, they broke up and Sidney married someone else a few years later.

Much of what I've learned has been from Sidney and her sister, Stefin. I've learned that you can change the environment, but you can't change the brain.

Sidney is nearly 30 now, married to a man in the Navy and running her own cat-sitting business. Her successes are due in part to our family working with her schools over the years and learning to cope with the realities of FAS. I have also learned to cope with the shame, guilt, grief, and pain that accepting her condition brought to the surface. Although the situation appeared hopeless, I refused to believe that. If we don't get past anger, we're stuck. We need to go through grief to acceptance. Then we can start learning and get to the point where our emotions aren't driving what we do.

Much of what I've learned has been from Sidney and her sister, Stefin. I've learned that you can change the environment, but you can't change the brain. I can help them make their lives as positive as they possibly can be: happy, comfortable, and functional. But I do remember feeling inadequate, helpless, frustrated, and scared as a parent. I tried to make decisions that were

practical and seemed to fit the problem, but they were not decisions that other parents agreed with. Because each child with an FASD is unique, parents need to avoid comparing children or generalizing about how to parent them. We need to share our joy in our children's successes and have compassion for those who struggle if we are to figure out what works.

I am part of the newly forming birth mothers network with the FASD Center for Excellence. We hope to support birth mothers and remove the stigma of FASD. Through my counseling work and other efforts, I have met many parents and shared my story. It has been a large part of my recovery and I look forward to meeting more parents in the future. I hope one day, though, that there won't be any parents of children with FASD because we will have found a way to prevent FASD. All women deserve healthy pregnancies and children deserve healthy lives.

Marceil Ten Eyck is a therapist in private practice in Kirkland, Washington. She is a member of the SAMHSA FASD Center for Excellence Steering Committee, birth mothers network, and training team.

Editorial Guide

We welcome your thoughts on newsletter topics and other issues. E-mail fascenter@samhsa.gov and include "FASD Center newsletter" in the subject line. Or write to FASD Center Newsletter Editor, 1700 Research Boulevard, Suite 400, Rockville, MD 20850. Include your name, city, and State. Unless otherwise requested, letters may be published with the author's name and location. Letters may be edited for space and content.

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.



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