*Substance Abuse and Mental Health Services Administration*
*Center for Substance Abuse Prevention*
*Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence*

# Building FASD State Systems 2012 Conference

## *Capitalizing on Awareness: Bringing the FASD Message to the Forefront*

## A Summary of the Plenary and Breakout Sessions of the Building FASD State Systems Conference and Affiliated Meetings

### Arlington, Virginia • April 30–May 3, 2012

**Report submitted: June 11, 2012**

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Electronic versions of the majority of the presentations summarized herein are available on the FASD Center for Excellence Web site (www.fasdcenter.samhsa.gov).

# BFSS 2012 Conference: Background and Planning

## History

The Substance Abuse and Mental Health Services Administration (SAMHSA) Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence (FASD CFE) convened the ninth Building FASD State Systems (BFSS) Conference May 1–3, 2012, in Arlington, Virginia. This annual event supports the FASD CFE's legislative mandate to provide technical assistance (TA) to communities developing systems of care, and is designed to further specific FASD CFE goals, including:

- Advancing the field of FASD;
- Facilitating the development of comprehensive systems of care for FASD prevention and treatment;
- Building infrastructures to ensure that FASD gets critical resources required for lasting change;
- Identifying components of a comprehensive system of care for individuals who have an FASD; and
- Incorporating evidence-based interventions and prevention practices.

## Attendees

A wide range of participants are invited to the BFSS conference each year, with an emphasis on State and U.S. Territory government employees involved in issues related to FASD and policymaking. The sessions include voices from across the entire spectrum of support and services to people with an FASD, including representatives from primary care, the public and private sectors, criminal justice and social services, birth mothers and family members, individuals with an FASD, advocates, counselors, educators, administrators, mental health and substance abuse treatment professionals, researchers, and scientists.

**BFSS 2012**
**Attendees At-a-Glance**

Participation at this year's conference represented a 19 percent increase from the 2011 conference and a 28 percent increase from the first BFSS conference in 2003. There were **281 participants** from:

- **48 States** and the District of Columbia
- **2 U.S. Territories** (Virgin Islands and Guam)
- **Native American Communities**

This year's sessions featured representatives from 48 States (North Dakota and Rhode Island were not represented), two U.S. Territories (Virgin Islands and Guam), Washington, D.C., and the Navajo Nation. Attendees included local, State, and juvenile court subcontractors implementing FASD intervention programs, as well as members of the FASD CFE's Expert Panel, the American Indian/Alaska Native/Native Hawaiian Expert Panel (Native Expert Panel), the National Association of FASD State Coordinators (NAFSC), the Birth Mothers Network (BMN), and the Self Advocates with FASD in Action (SAFA) Network. Other agencies represented included the National Organization on Fetal Alcohol Syndrome (NOFAS), the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS), The Arc of the United States, Children and Families First, Prevention First, ZERO TO THREE, the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the Centers for Disease Control and Prevention (CDC), as well as representatives from universities throughout the country.

## Planning the Conference

Each year, a BFSS Planning Committee helps formulate the conference agenda and activities. This Committee consists of individuals from the field, working with the SAMHSA Contracting Officer Technical Representative (COTR), SAMHSA Alternate COTR, and staff from the FASD CFE. The Committee meets by teleconference as often as necessary to accomplish the needed tasks. In selecting Planning Committee members, FASD CFE staff looks for representation from:

- Diverse geographic locations;
- States at all levels of FASD systems development;
- Various organizations;
- States that have received a local community and/or State subcontract, as well as non-funded States;
- A mix of cultures and ethnicities;
- The meeting's host State; and
- Previous Planning Committee members.

The BFSS 2012 Conference Planning Committee began working in January 2012. They developed the conference theme and reviewed and recommended plenary and breakout session topics and potential speakers. Many Committee members also introduced speakers and served as session moderators and panelists at the conference.

**BFSS 2012 Planning Committee**

- Jerri Avery (Mississippi)
- Mercedes E. Alejandro (Texas)
- Leigh Ann Davis (Texas)
- Pamela Gillen (Colorado)
- LaShaunda Harris (Washington)
- Amy C. Hendricks (North Carolina)
- Barbara Jacobs (Ohio)
- Martha Kurgans (Virginia)
- Jeri Museth (Alaska)
- Kathy L. Paxton (West Virginia)
- Carol F. Rangel (Arkansas)
- Barbara M. Wybrecht (Michigan)
- Rob Wybrecht (Michigan)

Arlington, Virginia was chosen as the site for BFSS 2012 conference to ensure participation by Federal representatives and due to the general accessibility of the Washington, D.C. area. As the theme for this year's event, the Planning Committee chose *Capitalizing on Awareness: Bringing the FASD Message to the Forefront.* The theme is a subtle reference to the proximity of the Nation's Capitol (an image that was used on a variety of meeting materials) while also emphasizing the profound growth in awareness surrounding FASD since the first BFSS conference in 2003.

As was done last year, the FASD CFE sent out a call for abstracts for the conference. The FASD CFE received 33 abstracts for presentations. The Planning Committee reviewed the FASD CFE's top selections and gave their recommendations on ways to maximize the number and diversity of presentations (e.g., by adding another round of breakout sessions and combining speakers into broadly themed panels).

# Conference Overview

## Registration, First-Time Attendees' and Mini-Training Sessions, Opening of the Poster and Exhibit Display—Tuesday, May 1, 2012

BFSS conference participants began registering for the conference at 3:00 p.m. on Tuesday, May 1. Later that afternoon, interested participants attended *We're Glad You're Here: BFSS First Time Attendees' Session*, presented by the FASD CFE's Project Director, Callie B. Gass. Afterward, Dan Dubovsky, M.S.W., the FASD CFE's FASD Specialist, and Julie Gelo, Executive Director of NOFAS Washington State, presented a well-attended FASD mini-training titled *I Am Me—Person-First Language*. Concurrently, the SAFA Network opened the first session of its meeting.

Beginning at 6:00 p.m., the FASD CFE staged the annual opening of the Poster and Exhibit Display, during which the FASD CFE's 23 subcontractors and other presenters shared materials about FASD activities in their States. Morgan Fawcett, a Native American flute player, provided music during the session and shared information about his music and his passion for FASD advocacy. Attendees used this session to network and learn about the work of other States.

## BFSS Conference—Structure of the Sessions

As in previous years, the conference included general plenary sessions attended by all participants, followed by breakout sessions that allowed participants to select topics that suited their needs and interests. There were two rounds of breakouts on the first day. Both included four topic-specific sessions. The second day of the conference featured four additional topic-oriented breakout sessions. Brief descriptions of the plenary sessions are provided below. Listings of the breakout sessions offered on each of the two meeting days follows. On both days of the BFSS conference, SAFA Network members and support persons met for an individualized meeting track during the BFSS breakout sessions. (Additional information on the SAFA Network Meeting is provided in the Affiliated Meetings section.)

## Day 1 Plenary Sessions—Wednesday, May 2, 2012

### Welcome and Introductions

Jon P. Dunbar-Cooper, M.A., CPP, COTR, SAMHSA FASD CFE, Public Health Analyst, Center for Substance Abuse Prevention (CSAP), SAMHSA

The BFSS conference began Wednesday, May 2 at 8:30 a.m. with remarks by Mr. Dunbar-Cooper. On behalf of SAMHSA, Mr. Dunbar-Cooper welcomed participants to the Washington, D.C. area and thanked them for coming to the conference. He noted that this was the last BFSS conference under the current FASD CFE contract, and the ninth conference held in the past 10 years. During the first conference, also held in Arlington, Virginia, there were 200 attendees representing 49 States and the District of Columbia. Since then the conference has grown to 281 participants, including nearly 100 representatives from affiliate groups that have been created along the way, such as the BMN and the SAFA Network. The desired outcome of the BFSS conference is to help participants achieve more and greater success in their work in the field of FASD.

## SAMHSA and FASD: Now and Into the Future

Introduction: Jon P. Dunbar-Cooper, M.A., CPP

Speaker: Richard Lucey, Acting Director, Division of Systems Development (DSD), CSAP, SAMHSA

Speaker: Patricia B. Getty, Ph.D., Alternate COTR, SAMHSA FASD CFE; DSD, CSAP, SAMHSA

Mr. Dunbar-Cooper introduced Mr. Lucey, who spoke on behalf of Frances Harding, CSAP Director, who was unable to attend due to a scheduling conflict. Mr. Lucey talked about his long career in prevention, the importance of FASD prevention and treatment efforts, and how far the field has come in 30 years. He then introduced the keynote speaker, Dr. Patricia Getty.

Dr. Getty looked back over the 10 years that the FASD CFE has been in existence. She discussed the Children's Health Act of 2000, which called for the creation of one or more centers of excellence to study and disseminate promising practices in the field of Fetal Alcohol Syndrome (FAS). She talked about the FASD CFE's goals—to eliminate alcohol consumption by pregnant women and to improve the functioning and quality of life of people with an FASD and their families. She outlined lessons learned along the way—that programs are about people, not statistics, and that the need for services exceeds availability. She talked about specific activities of the FASD CFE, such as the development of the Treatment Improvement Protocol (TIP); the groups that have grown out of the FASD CFE; and the efforts to coordinate with other agencies and organizations, such as the Interagency Coordinating Committee on FASD. She highlighted the Native Initiative and the recent Native Leaders Conferences that occurred in 2011 and 2012.

**SAMHSA's 2013 Budgetary Priorities**

- Substance Abuse Treatment and Mental Health Services
- Prevention
  - Substance Abuse Prevention
  - Mental Health State Prevention
  - Behavioral Health Tribal Prevention
- Testing and Delivering Targeted Interventions
  - Addressing Trauma
  - Assisting in Transitions from Homelessness
  - Preventing Suicide
  - Responding to Disaster
- Other Activities
  - Protecting Individuals with Mental Illness
  - Health Surveillance and Program Support

Dr. Getty then turned to the issue of the SAMHSA budget and future funding for the FASD CFE. She presented SAMHSA's budgetary priorities for fiscal year 2013. She said that the proposed 2013 budget, which reduces funding for the FASD CFE, was not necessarily going to be approved by Congress. She mentioned that the U.S. Government is a three-legged stool, and that that the seat of the stool is the people, such as those working in the FASD field, who can tell the government what is important to them. Dr. Getty then took questions from the audience and concluded the presentation by thanking the participants and the FASD CFE staff for their hard work to further the field of FASD.

## Report from the SAMHSA FASD Center for Excellence

Callie B. Gass, Project Director, SAMHSA FASD CFE

Ms. Gass provided participants with a brief history of the FASD CFE. She then presented highlights and outcomes from the past 10 years. They included:

- Innovative Field Interventions/Service Integration Strategies—The subcontractors work with women of childbearing age, and providing FASD diagnosis and intervention services;

- The number of training and TA events provided over the past 5 years—216 trainings and TA events to 9,000 participants in 32 States and Canada;
- The provision of training/TA to develop FASD strategic plans in several States;
- The development of four learning communities among the FASD CFE's subcontractors and promising programs;
- The annual Field Trainers event, which trains attendees in the current knowledge on FASD so they can provide the most up-to-date FASD information to others in their States;
- The development of NAFSC, the BMN, and the SAFA Network;
- The BFSS conference;
- The Native Initiative;
- Information dissemination and product development activities, including the first SAMHSA TIP developed by CSAP, and the number of products downloaded from the Web site; and
- The conferences where FASD CFE staff have presented on FASD, such as the American Public Health Association (APHA), the National Prevention Network, and the Indian Health Service (IHS), among others.

Ms. Gass then summarized the progress made over the past 10 years in the areas of resources and services. She stated that:

- Between 2003 and 2012, States have reported significant increases in activities designed to provide greater services for families affected by FASD;
- Between 2009 and 2012, States have reported significant increases in the availability of trained staff and resources to meet State needs for FASD prevention and treatment; and
- Between 2009 and 2012, there was a 7 percent increase in States reporting partnerships with the BMN.

Ms. Gass concluded by saying that though great progress has been made and the work of the past 10 years has laid a solid foundation, there is still a long way to go. She said that moving forward, the field needs to create sustainability for FASD programs and achieve a fully networked system of government agencies and programs.

## Expanding State and Local Capacity to Screen, Diagnose, and Provide Services to Children and Youth With an FASD

Moderator: Susan J. Astley, Ph.D., Professor of Epidemiology/Pediatrics; Director, Washington State FAS Diagnostic and Prevention Network

Speakers:

- Christopher Boys, Ph.D., LP, Assistant Professor of Pediatrics; Pediatric Neurospsychologist; Co-Director, Fetal Substance Exposure Program; Department of Pediatrics; University of Minnesota Medical School
- David Deere, M.S.W., M.Th., Director, Partners for Inclusive Communities, University of Arkansas for Medical Sciences
- Anthony A. Perszyk, M.D., FAAP, DABP, DABMG, Pediatric Department, Pediatric Multispecialty Center, University of Florida-Jacksonville

Dr. Astley talked about the ways that States can move forward on issues related to FASD. She presented the process that Washington State went through over the past 40 years, describing how the legislature and Federal sources (such as CDC) provided needed resources to expand FASD diagnostic clinics across the State. After 40 years, the State of Washington has numerous diagnostic clinics, they screen children in foster care for FASD, they have programs such as the Parent–Child

Assistance Program (P-CAP), they provide training on FASD, there is an FASD State coordinator, and they have formed an interagency work group on FASD. The State developed a comprehensive document of their 40 years of effort in FASD and posted it on the State Web site.

Dr. Boys presented information about how the University of Minnesota developed a program for screening children for FASD and how they worked with the public school system to keep children adjudicated for truancy at home rather than in programs. MOFAS provided initial funding and then, later, the schools produced funding to sustain the program. The lessons they learned included recognizing that many children in the juvenile justice system have FASD but are undiagnosed, and that a relationship between the courts and the diagnostic clinics is critical.

Mr. Deere provided an overview of FASD in Arkansas and how the BFSS Conference and the FASD CFE helped them build their State system. They viewed the subcontract with the FASD CFE as a jump start to increasing awareness of FASD and State partnerships to address the issue. Mr. Deere recommended that others identify potential partners within their States that can be approached about coordinating efforts to prevent and treat FASD.

Dr. Perszyk opened with a discussion of the community-based programs in Florida with which the University of Florida-Jacksonville works. Their process includes the involvement of Child Guidance Center, occupational therapy, and psychoeducational, speech/language, and medical evaluations. A key component is educating the parents of children with an FASD and providing intervention services. They also provide training to providers in various care settings in recognizing FASD, referring children for screening, and counseling parents on when to change approaches with their child.

## Evidence-Based Interventions for Children With an FASD

Moderator: Jacquelyn Bertrand, Ph.D., Behavioral Scientist, National Center on Birth Defects and Developmental Disabilities, CDC

Speakers:

- Ira J. Chasnoff, M.D., President, Children's Research Triangle, Professor of Clinical Pediatrics, University of Illinois College of Medicine-Chicago
- Elizabeth Laugeson, Psy.D., Assistant Clinical Professor, Department of Psychiatry and Biobehavioral Sciences, UCLA Semel Institute for Neuroscience and Human Behavior
- Molly Millians, D.Ed., Education Specialist, FAS Clinic, Marcus Center
- Anika Trancik, Ph.D., Behavioral Services, The Florida Center for Child and Family Development, Consulting/Staff Psychologist, Comprehensive Medpsych Systems

Dr. Chasnoff talked about the program Parents and Children Together (PACT), and a study conducted with 75 foster children with deprivation and FAS/Alcohol Related Neurodevelopmental Disorder. The goal was to improve neurocognitive functioning in the areas of executive function and behavioral and emotional regulation. The treatment course lasted 12 weeks, and each group session was 75 minutes, with simultaneous children's groups and parent's groups (the two groups combined for the last 10-15 minutes). The results showed significant improvement in the children's executive function and emotional regulation.

Dr. Laugeson presented on Project Good Buddies, a friendship training program for children with an FASD initially funded with a CDC grant. This type of training teaches a variety of skills, including how to interact with friends, how to enter a group of children already playing with each other, help with in-home play dates, and ways to avoid conflict and use negotiation skills.

Participants and parents in the program reported significant improvement in social skills knowledge, self-esteem, and overall social skills.

Dr. Millians presented information on the Math Interactive Learning Experience (MILE) program for children with an FASD. A study was done on MILE, supported by CDC. The program's goals are to support, educate, and empower caregivers; achieve learning readiness; and improve math achievement in a known area of deficit often noted in children affected by prenatal alcohol exposure. The conclusions were that children with an FASD can make improvements in learning readiness and behavior management when provided with interventions that encompass parent training. This training should include information about the neurodevelopmental delays associated with prenatal alcohol exposure and an understanding of the social learning principles of behavior and strategies to address challenging behavior.

Dr. Trancik provided an overview of the program Families Moving Forward (FMF), which helps children with an FASD, their families, and the professionals who work with them. A study of the program showed high treatment participation and illustrated the intervention's feasibility. In addition, the study showed that the program resulted in an increased sense of efficacy in parents, and that treatment met families' needs.

## Day 2 Plenary Sessions—Thursday, May 3, 2012

### Current Science and Research Trends in the Field

Moderator: Carol Rangel, FASD Project Director, Division of Children and Family Services, Arkansas Division of of Child and Family Services

Speaker:

- Rajesh C. Miranda, Ph.D., FASD Study Group President, Professor, Texas A&M Health Science Center, College of Medicine, Department of Neuroscience & Experimental Therapeutics

Dr. Miranda provided an update on the FASD Study Group activities. This year the group meeting, which will be held in June in San Francisco, will focus on biomarkers and legal and ethical issues. He then talked about using data from the Collaborative Initiative on Fetal Alcohol Spectrum Disorders and SAMHSA's National Survey on Drug Use and Health in his research activities. Dr. Miranda then presented detailed scientific discussions about current research trends in the areas of mechanisms underlying teratology, detection of fetal ethanol exposure, and therapeutic intervention strategies. He summarized his discussion in his concluding remarks:

- Ultrasound is a potential tool for detecting alcohol exposure in utero;
- Nutrition can be an important protective factor—for example, choline could help protect a fetus from alcohol exposure; and
- Mice studies suggest that alcohol exposure in utero could make the offspring more susceptible to diseases, such as breast cancer, but more study is needed at this time.

### Don't Forget the Siblings…We Have the Longest Lasting Relationship With Our Brothers or Sisters with an FASD

Introduction: Leigh Ann Davis, M.S.S.W., M.P.A., Project and Information Specialist, Chapter Excellence, The Arc, SAFA Network Liaison

Speakers:

- Lynnae Wybrecht Selberg, M.A., LPC, LSW, CRC, Program Director of Counseling/ Department Head, Grand Rapids Community College

- John McAndrew, FASD Advocate

The session was presented by siblings of two SAFA Network members, sharing their experiences growing up with a brother with an FASD. When there is an individual in the home with a significant disability, many times the siblings are overlooked. The presenters emphasized how important it is to treat the whole family, not just the individual with an FASD. For most brothers and sisters, their future and the future of their siblings with an FASD are inexorably entwined. Despite this, there is little funding to support projects that will help individuals with an FASD get the information, skills, and support they will need throughout their lives. The session included music performed by John McAndrew, a professional musician who has released several albums and scored a number of films.

## Day 1 Breakout Sessions—the First Round

### FASD Prevention Efforts in Massachusetts

Moderator: Norma Finkelstein, Ph.D., LICSW, Executive Director, Institute for Health and Recovery, Massachusetts

Speakers:

- Enid Watson, M.Div., Massachusetts FASD State Coordinator, Massachusetts Department of Public Health
- Kathleen Herr-Zaya, Ph.D., Public Information Coordinator, Prevention Unit, Massachusetts Bureau of Substance Abuse Services
- Karen Pressman, LCSW, LADC1, Director, Planning and Development Unit, Massachusetts Bureau of Substance Abuse Services

The Massachusetts Bureau of Substance Abuse Services stepped up efforts to increase substance abuse prevention and services across the State, resulting in more initiatives, resources, and services available to the FASD prevention community. For example, all State detoxification facilities were required to treat pregnant clients, including those with alcohol addiction (as mandated by SAMHSA's block grant). A task force, developed to address pregnancy-specific alcohol use, spearheaded efforts to determine effective alcohol screening tools and develop FASD prevention training. Presently under consideration are screening tools that target risky use rather than addictive alcohol consumption in pregnant women. Although the American Congress of Obstetricians and Gynecologists has endorsed T-ACE as the screening tool of choice, the task force stresses a no-alcohol approach. Ms. Watson, as an FASD State coordinator, offers statewide FASD prevention training at no cost.

**Day 1: The First Round of Breakout Sessions**

- FASD Prevention Efforts in Massachusetts
- Addressing PAE/FASD in Recovery Programs for Pregnant and Parenting Women With Substance Use Disorders Utilizing Federal Block Grant Funds
- Teach the Children Well: A Comprehensive Education Project for FASD Prevention and Intervention
- Call to Jury Duty: Law and Ethics of Alcohol Use in Pregnancy

Now available in all participating community- and health-centered facilities across the State is the Massachusetts Screening, Brief Intervention, Referral, and Treatment program (MASBIRT). This federally funded initiative universally screens, identifies, and offers resources to patients dealing with drug- and alcohol-related issues. Although there is no designated FASD diagnostic clinic in Massachusetts, a newly formed FASD

task force, in concert with two doctors from Children's Hospital, is focusing on increasing diagnostic capacity for both children and adults.

## Addressing PAE/FASD in Recovery Programs for Pregnant and Parenting Women With Substance Use Disorders Utilizing Federal Block Grant Funds

Moderator: Carol Rangel

Speakers:

- Sue Terwey, M.S., Family Engagement Director, MOFAS
- Ruthie Dallas, State Planner Principal/Women Services Consultant, Treatment Services Section, DHS Chemical and Mental Health Services Administration, Alcohol and Drug Abuse Division

The speakers illustrated how they modified approaches to achieve better outcomes for women in substance abuse treatment through the use of collaborative relationship between MOFAS and the Minnesota Department of Human Services. This relationship was part of a broader alliance consisting of a variety of stakeholders. Involvement of a women's services coordinator was particularly critical as she brought on board treatment providers who had been resistant. The alliance conducted meetings to discuss making FASD a priority with block grant spending. Other actions they took included determining the lead on coordination of training, identifying the process for incorporating questions on prenatal alcohol exposure (PAE) into screening, and working with the FASD CFE for TA.

This project provided an opportunity to offer education, support, and early intervention and identification services. Staff was trained on FASD—modifying treatment, using the FASD toolkit for women in recovery, parenting, and addressing red flag responses to intake questions. Public health nurses and program staff were equipped to screen children for a history of prenatal exposure with appropriate documentation, refer children for evaluation, and modify treatment as needed. Birth moms and dads were offered support through the Hand in Hand series, which focuses on parenting children with an FASD. Support is also offered to birth mothers through the BMN. Training and TA is offered and site visits are conducted to assist, promote, and modify the program as needed to enhance its success.

## Teach the Children Well: A Comprehensive Education Project for FASD Prevention and Intervention

Moderator: Pamela Gillen, N.D., R.N., CACIII, Director, COFAS Prevention Project, Anschutz Medical Campus, University of Colorado Denver

Speakers:

- Helen Weinstein, CPP, Coordinator, Fetal Alcohol and Drug Effects Program, Erie County Council for the Prevention of Alcohol and Substance Abuse
- Erica J. Boyce, MCJ, Community Educator, Erie County Council for the Prevention of Alcohol and Substance Abuse

Ms. Weinstein and Ms. Boyce co-presented this session on effective school-based FASD intervention techniques that foster success for students with an FASD and help prevent secondary disabilities. Components of their project in Erie County, New York, are targeted to middle- and high-school students, college students, and education professionals. During the workshop, they presented ideas on how to integrate FASD awareness into the educational system:

- Contact school health departments/teachers, nurses;

- Provide volunteer presentations to diversified school profession audiences;
- Conduct train-the-trainer sessions;
- Influence teachers and parent to "advocate" and spread the word;
- Form partnerships with like-minded people; and
- Show the true value of integration (not only informative, but can also be fun).

Small group activities are used for motivating and engaging workshop participants in the same manner that students and educators are engaged. This program is currently being evaluated through a contract with the Center for Health and Social Research, located at Buffalo State College. Results of this research and evaluation tools will be shared. During the 2010–2011 academic year, over 3,000 students and educational professionals (2,475 middle- and high-school students; 237 college students; and 325 principals, teachers, and support personnel) participated in this educational project.

### Call to Jury Duty: Law and Ethics of Alcohol Use in Pregnancy

Moderator: Amy C. Hendricks, FASD State Co-Coordinator, Project Director, North Carolina Fetal Alcohol Prevention Program

Speakers:

- Carolyn Szetela, Ph.D., Associate Professor, Department of Professional and Medical Education, Meharry Medical College
- Eileen Bisgard, J.D., 17th Judicial District FASD Project, Executive Director, NOFAS Colorado

Dr. Szetela and Ms. Bisgard presented an activity that can be used to facilitate a discussion of how ethics and legal interventions might impact the prevention of harm from maternal drinking during pregnancy. (The presenters noted that offering ethics credits to lawyers who participate is an effective way of educating an influential group about FASD.) The training begins by emphasizing that alcohol is the substance of abuse most damaging to unborn children. Presenters also explain FASD, its prevalence, and the effects of prenatal alcohol exposure. They then show an episode of *Law and Order: SVU* in which a court attempts to mandate inpatient treatment for a woman who is pregnant and has a history of drinking while pregnant.

After watching the clips, attendees break into smaller groups of "juries" and answer the following question: Should the woman be sentenced to mandatory inpatient treatment for her alcohol use during pregnancy? Of the seven juries in the room, four were hung while three committed to putting her in treatment (one unanimously). This led to an open-ended discussion of individual rights versus the rights of the unborn. The presenters spoke about the stance a number of organizations have on forced treatment for pregnant women, and laws that are currently on the books or that are being debated that will impact the legalities surrounding protecting fetuses from alcohol exposure.

## Day 1 Breakout Sessions—the Second Round

### Examining the Impact of a 2-Hour Research-Based Curriculum Infusion on Nursing and Social Work Students

Moderator: Jerome Romero, Director, FASD Prevention Program, University of New Mexico

Speakers:

- Joyce Hartje, Ph.D., Evaluator, Mountain West Addiction Technology Transfer Center Network, Center for the Application of Substance Abuse Technologies, University of Nevada, Reno
- Teresa Kellerman, Director, FAS Community Resource Center, Arizona

In an effort to rectify the lack of substance abuse-related instruction in college undergraduate programs, the Center for the Application of Substance Abuse Technologies at the University of Nevada, Reno, formed the Frontier Regional FASD Training Center to develop discipline-specific curriculum infusion packages (CIPs) for nursing and social work students. Research shows that students are more likely to retain and practice what they have learned in an academic setting than they are in a less formal context. With this in mind, the training center generated a 2-hour course—including PowerPoint slides, videos, classroom exercises, and an instruction manual—which encompassed all necessary FASD information for inclusion in a college curriculum. Key lessons learned over time: (1) Need a champion within the department; (2) Nursing programs have the most difficulty fitting CIPs into their curricula; (3) Two 1-hour modules worked best; (4) Using case studies was essential; (5) Important to identify addiction as a chronic disease process.

Teresa Kellerman and her adopted son John, who has an FASD, shared the presentation *A Personal Account of John's Life*. On Ms. Kellerman's Web site (www.fasday.com) are resources (including John's story) for putting together an FASD Day awareness event. Her other site, www.fascrc.com, contains links to relevant articles on research, diet recommendations, social skills, books, brochures, skits, adoption of children with an FASD, and working with youth.

## Changing the Environment to Prevent FASD: The Kentucky Experience (A Work in Progress)

Moderator: Amy C. Hendricks

Speakers:

- Laura Nagle, CPS, FASD Coordinator, Bluegrass Regional MH/MR Board, Inc.
- Yasmin Senturias, M.D., Developmental-Behavioral Pediatrician, FASD Clinic, University of Louisville
- Donna Wiesenhahn, M.Ed., Regional Prevention Director, Bluegrass Regional MH/MR Board, Inc.

**Day 1: The Second Round of Breakout Sessions**

- Examining the Impact of a 2-Hour Research-Based Curriculum Infusion on Nursing and Social Work Students
- Changing the Environment to Prevent FASD: The Kentucky Experience (A Work in Progress)
- Collaboration and Caring: Changing Social Norms by Engaging Prenatal Care Providers in Your State
- Collaborating With Native Leaders and Elders to Support Community and State FASD Prevention and Intervention Efforts

Presenters in this session shared information on four different projects they have implemented across their State, aimed at educating OB/GYN physicians on FASD and trying to move them to consistent messages on drinking alcohol while pregnant. Over the past 2 years the group has cultivated a volunteer network of hundreds of people they call on to assist with some of their awareness and education projects. Their philosophy: (1) Community change must be fun, and (2) involvement leads to passion. Projects include:

- A single-week blitz of delivering a videotape on alcohol-exposed pregnancy and FASD to OB/GYN and other physicians' offices and other organizations across the State. There were more than 500 showings of the tape during 1 week.
- Personal delivery of a survey to every OB/GYN in the State. Surveys were given to office managers along with chocolates. They were asked to encourage the doctor to answer and

return the survey. This garnered a 45 percent response rate; it showed that 88 percent of doctors do not think pregnant women or women who can get pregnant should drink alcohol.
- Monthly FASD reminder postcards mailed to OB/GYN physicians, along with postcards to office managers, which encourage them to give the doctor their postcard.
- Creation of a Facebook feedback loop that rewards office managers and others who respond with comments through monthly incentive drawings.

They are working on a 5-year plan to gain greater access to OB/GYN physicians, influence the type and consistency of messages doctors give pregnant woman on drinking alcohol, and create a statewide volunteer training network.

## Collaboration and Caring: Changing Social Norms by Engaging Prenatal Care Providers in Your State

Introduction/Moderator: Carol Rangel

Speakers:
- Cecily Hardin, LCSW, FASD Coordinator, Child Guidance Center
- Chelsea Hoffman, FASD Case Manager and Data Specialist, Child Guidance Center
- Renee Owens, M.H.S., OTR/L, Pediatric Occupational Therapist

The Child Guidance Center (CGC) in Jacksonville, Florida, has successfully integrated screening, diagnosis, and interventions for children with an FASD in a community behavioral health setting and has screened 702 children ages 0–7 from November 2011 through March 31, 2012. Of those screened, the following outcomes were noted:

- 79 were positive (11 percent of screenings);
- 74 were referred to full screening (93 percent of positive screenings);
- 51 completed diagnostic evaluations (70 percent of children referred); and
- 46 children were diagnosed with an FASD (6.5 percent of total screenings).

The CGC speakers focused on the challenges and resources available to workaround integration issues such as case management, diagnosis, and reimbursement. With an integrated approach, providers from various and related disciplines presented evaluations and recommendations that were combined into one summary report for the child being assessed. Behavioral health providers alone cannot deal with all of the issues of children with an FASD. In addition, there is a major requirement that occupational therapists be knowledgeable about sensory processing disorder and three hidden senses:

- Interoceptive: Sensory system of the internal organs (e.g., heart rate, hunger, digestion, state of arousal, mood, etc.);
- Vestibular: Processing information about movement, gravity, and balance, primarily received through the inner ear; and
- Proprioceptive: Processing information about body position received through the muscles, ligaments, and joints.

Final thoughts regarding clinical reimbursement involved the use of comprehensive case management, which is a service that is billable through the Florida Medicaid system. Facilities can bill for attention deficit hyperactivity disorder where FAS is not the primary or lead diagnosis, but an underlying diagnosis.

## Collaborating With Native Leaders and Elders to Support Community and State FASD Prevention and Intervention Efforts

Moderators:

- Jerri Museth, M.S.W., Wellness Coordinator, Tribal Family and Youth Services, Central Council of the Tlingit and Haida Indian Tribes of Alaska
- Kim Ku'ulei Birnie, Communications Director, Papa Ola Lokahi

Speakers:

- Melody Price-Yonts, M.S., CDC 1, Division Director, Behavioral Health, Southeast Alaska Regional Health Consortium
- John Anson Hau'oli Tomoso, M.S.W., ACSW, LSW, Executive Director, Hui No Ke Ola Pono, Inc., The Native Hawaiian Health Care System for Maui
- L. Diane Casto, M.P.A., Manager, Prevention and Early Intervention Services, Alaska Division of Behavioral Health, Alaska Department of Health and Social Services
- Naomi Imai, M.Ed., CRC, Child and Youth Program Specialist, Family Health Services Division, State of Hawaii Department of Health

The moderators began with an overview of three Native Leaders Conferences conducted by the FASD CFE. They noted that the goal of each was to increase commitment to addressing the prevention and treatment of FASD. The objectives of the conferences were:

- To discuss issues of FASD in Native communities, including challenges faced and resources needed;
- To provide networking opportunities; and
- To share methods and best practices.

The moderators said that in total, 172 individuals attended the three conferences, with representation from 18 States, 52 Tribes, 1 U.S. Territory, and 1 Freely Associated State.

The speaker noted that each of the conferences incorporated adjustments based on comments and suggestions made by participants at previous conferences. Ms. Casto and Ms. Price-Yonts said that the Alaska conference, which was held most recently, focused on presentations from Native Alaskans and on regional strategic planning sessions. In addition, the conference concluded with Federal participants responding to what occurred.

The speakers emphasized the cultural and geographic distance of Hawaii and Alaska from the U.S. mainland. They also noted that Native people have different cultures and organizational structures from each other and discussed the barriers to FASD prevention and treatment. The speakers concluded by talking about outcomes from the conferences:

- Initial discussions to reform three currently defunct FASD diagnostic teams (AK);
- Passage of two Tribal resolutions arguing for an improved effort to combat FASD (AK);
- Realization of the importance of including Tribal leaders in efforts to combat FASD (AK);
- Increased membership in a statewide FASD Partnership—led to passage of a bill that adds FASD to a list of mitigating circumstance that can be used at criminal trials (AK);
- The ability to meet and speak face-to-face with people who are separated by an ocean (HI);
- Increased interest in FASD by universities (HI);
- Created a relationship between the State's Child Welfare Services for the first time in 20 years (HI); and
- Conference was covered by the media, which spread the word about FASD (AK).

## Day 2 Breakout Sessions

As with Day 1, participants chose one of four available breakout sessions. SAFA Network members and their support persons once again attended closed sessions specifically developed for them.

### Effective Screening and Identification of Women Within WIC Clinics Who are At Risk for Alcohol Use While Pregnant

Moderator: Carol Rangel

Speaker:

- Roland Loudenburg, M.P.H., Senior Research and Evaluation Scientist, Mountain Plains Evaluation, South Dakota

In 2008, a collaboration of private, State, and Federal agencies developed an alcohol screening and intervention program for pregnant women in five (ten as of 2011) South Dakota WIC clinics, based on research by O'Connor and Whaley (Brief Intervention for Alcohol Use by Pregnant Women, *American Journal of Public Health*, Feb. 2007; 97(2): 252–258). This project did not overlap with Healthy Start work on Native American reservations in South Dakota. After pregnant women were screened, they received a 10- to 15-minute brief intervention if they had been drinking in the previous 30 days or if their T-ACE scores were two or more. Mr. Loudenburg's presentation illustrated the aggregated data from February 2012 in various forms.

**Day 2: Breakout Sessions**

- Effective Screening and Identification of Women Within WIC Clinics Who are At Risk for Alcohol Use While Pregnant
- The Safe Babies Court Team Projects: Supporting Alcohol-Exposed Women and Their Children in the Child Welfare System
- Alaska, the Last Frontier—But Not on FASD!
- The Twelve Steps Revisited for Individuals With an FASD and Their Families

In preparation for the project, Dr. Whaley trained WIC staff in screening and brief intervention techniques, and training continues at regular intervals via either site visits or conference calls. Now clinics share lessons learned—when a new site comes on board, its staff is paired with an experienced clinic's staff. According to Mr. Loudenburg, WIC personnel have greatly benefited from the information and training received.

### The Safe Babies Court Team Projects: Supporting Alcohol-Exposed Women and Their Children in the Child Welfare System

Moderator: Amy C. Hendricks

Speakers:

- Kimberly P. Diamond-Berry, Ph.D., Assistant Director, Safe Babies Court Teams Project, ZERO TO THREE
- Katherine Herrick, M.A., Project Coordinator, ZERO TO THREE

Representatives of the private, national, non-profit organization ZERO TO THREE described their successful *Safe Babies Court Teams* projects that operate in 10 cities across the country. They play the role of "cognitive partners" to parents, primarily women, whose children have been or are in danger of being removed from the home through court action. Data shows that 67 percent of parents appearing in this setting have a history of substance abuse, but the Court Team workers believe the number is higher. They approach their work with the assumption that 70

percent of children in the child welfare system have an FASD, that many of their mothers also are undiagnosed with an FASD, and that an undiagnosed parent cannot support a child's developmental needs. These court systems aim for family reunification, so to assist with this the Court Teams:

- Train professionals in the justice and social services systems on FASD and facilitate collaboration on services for the children, parents, and families;
- Identify the children who need a diagnosis;
- Identify the needs of the caregivers and, if need be, get a diagnosis and services for parents;
- Recognize that mothers with an FASD may lack self-regulation and the ability to plan and schedule, behave impulsively, and have poor reading skills and limited ability for verbal understanding; and
- Train staff and key people in the courts (especially judges), social services, attorneys, and other stakeholders on how to have productive interactions and reasonable expectations with children and parents who have an FASD.

Another project within the organization, Birth to Five, focuses on ensuring that FASD is included on the list of things to consider if a child exhibits physical or behavioral issues. They want to see FASD screening included in all public health home visitation programs that serve pregnant women and new mothers. Early intervention is key, they said. "We want to get the [birth] delivery doctors to ask each mother, 'When was your last drink?'", as opposed to "How much or how often do you drink?" They believe that is a truer measure of alcohol-exposed pregnancy.

## Alaska, the Last Frontier—But Not on FASD!

Moderator: L. Diane Casto, M.P.A.

Speakers:

- Trish Smith, Director of Prevention/Intervention Services, Volunteers of America, Alaska
- Tommy O'Malley, FASD Program Manager, Stone Soup Group

Ms. Smith and Mr. O'Malley alternately presented information detailing the historical perspective of FASD in the State of Alaska and its current status. FAS initiatives began in Alaska with IHS funding from the early 1990s. Work was actually initiated in 1997; however, the Alaska Office of FAS was established in 1998. U.S. Senator Ted Stevens received $20 million for the project. This earmark ended in 2006. Currently, funding is high due to increased oil and fuel prices. Recent legislative highlights include Senate Bill 127, officially designating September 9 as an Awareness Day, and Senate Bill 151/House Bill 367 establishing FASD as a mitigating factor for use at criminal sentencing.

Ms. Smith and Mr. O'Malley also pointed out the importance of statewide partnerships. There are over 56 organizations in 18 communities that identify the systems already in place to build into existing services and alliances advocating FASD. In addition, the Anchorage Council on FASD was started in 2002. Some of the following initiatives have resulted from the Council:

- Networking meetings;
- Statewide poster contests;
- Library partnerships for FASD Awareness Day observances;
- Bike helmet safety; and
- FAScinating Family Camp for children with an FASD.

In closing, Ms. Smith and Mr. O'Malley acknowledged that establishing statewide partnerships and "telling our stories" are vital to furthering the cause of FASD now and in the future.

## The Twelve Steps Revisited for Individuals With an FASD and Their Families

Moderator: Pamela Gillen, N.D., R.N., CACIII

Speaker:

- Kathleen Mitchell, M.H.S., LCADC, Vice President and Spokesperson, NOFAS

Ms. Mitchell provided an overview of ways in which twelve-step programs can be adapted for people with an FASD and their families. Ms. Mitchell noted that she disagrees with people who say the twelve-step method cannot work for people who have an FASD; however, she noted that the methods work better if steps are adapted, specifically if abstract concepts are made concrete. Ms. Mitchell began with a history and overview of the twelve-steps, emphasizing the importance of anonymous participation and reminding participants that she neither spoke for nor represented any specific twelve-step program. In terms of adapting the twelve-steps to individuals with an FASD, she noted that a strong, trustworthy sponsor is important to guide the individual through the process.

Ms. Mitchell then went through each step, using step three, "[We] made a decision to turn our will and our lives over to the care of God as we understood Him," to illustrate methods for converting abstract concepts into concrete actions. To this end, she passed note cards to participants and asked them to write down something that has been bothering them, something that cannot be changed. Then participants placed the note cards into a "God box," marking a concrete action that showed they are turning themselves over to a higher power. Other concrete steps included writing lists when asked to take an inventory and burning the list to show that the individual was moving beyond past mistakes. In addition, Ms. Mitchell suggested providing individuals with an FASD a notebook to write down questions that arise during meetings.

# Affiliated Meetings

To aid in the development of a comprehensive system of care for individuals with an FASD and their families, the FASD CFE established support groups, grassroots organizations that affect policy change, and panels of experts to guide the FASD CFE's work. These groups generally meet at BFSS and include:

- The Birth Mothers Network;
- The National Association of FASD State Coordinators;
- The FASD CFE's overall Expert Panel;
- The FASD CFE's Subcontractors;
- The American Indian/Alaska Native/Native Hawaiian Expert Panel; and
- The Self Advocates with FASD in Action Network.

Below are brief synopses of the work accomplished at the affiliated meetings held April 30 and May 1 in Arlington, Virginia.

## The Birth Mothers Network—Monday, April 30, 2012

The FASD CFE and NOFAS convened the annual BMN Business Meeting on April 30, 2012. Twenty-six members were in attendance. The agenda included updates from SAMHSA, NOFAS, and BMN State coordinators. NOFAS Vice President and BMN Program Director, Kathleen T. Mitchell, M.H.S., LCADC, also discussed member mentoring, support niches, and ideas for promoting the goals of the group—improving and strengthening the lives of birth families, providing peer support for birth families, and decreasing the stigma, blame, and shame that birth families may experience. Presenters also provided the group with information on sustainability and advocating for supports for children within the school system.

## National Association of FASD State Coordinators—Monday, April 30, 2012

The FASD CFE convened the annual face-to-face meeting of NAFSC on April 30, 2012. Twenty-three State coordinators (two participated via phone), five member stand ins, and seven visitors, including individuals from States interested in creating State coordinator positions, participated in the meeting. The NAFSC agenda included updates from SAMHSA, the BMN, the SAFA Network, the National Prevention Network, and NAFSC State coordinators. Chair Jerome Romero and Vice Chair Margo Singer, M.P.A., also discussed the accomplishments and future of the NAFSC subcommittees and issues related to the sustainability of the group.

## Expert Panel—Tuesday, May 1, 2012

This meeting marked the Expert Panel's final gathering under the current contract. The agenda included a review of action items from its December 7, 2011 meeting, an update from the SAFA Network, and a report from members affiliated with Federal agencies (including the Interagency Coordinating Committee on FASD, NIAAA, and CDC). In addition, the FASD CFE's senior staff presented a 5-year wrap-up, highlighting accomplishments since the beginning of the second contract in 2007.

- Mr. Dubovsky reported on training and TA efforts, paying particular attention to inroads made with private insurers and work with women's substance abuse programs.
- Mr. Dubovsky also provided an update on the FASD CFE's Native Initiative, illustrating the FASD CFE's direct impact on treatment methods in specific Native communities as well as noting outcomes of the three Native Leaders Conferences sponsored by the FASD CFE.

- Sue Kimner presented on the FASD CFE's information dissemination accomplishments, providing statistics on the the information resource center and Web site as well as an update on the development of products such as the FASD TIP, illustrated booklet for consumers, and revisions of the Native Resource Kit.
- Vinitha Meyyur, Ph.D., spoke about service-to-science and science-to-service projects, noting that four programs under the FASD CFE's review were accepted to and participated in SAMHSA's Service-to-Science academy; she also spoke about the conference-call-based learning communities participated in by 15 of the FASD CFE's subcontractors.
- Jill Hensley, M.A., updated the panel on the work of the FASD CFE's 23 subcontractors, providing the latest data culled from the subcontractor sites.

The meeting concluded with a discussion of the future of the FASD CFE.

## FASD Subcontractors—Tuesday, May 1, 2012

The Coordinating Center of the FASD CFE oversees 23 subcontracts that are implementing prevention, diagnosis, and intervention programs. The programs include States, Tribal courts, juvenile dependency and delinquency courts, and local providers.

The subcontractor meeting began with comments from Ms. Hensley, Project Manager of the FASD CFE FASD Coordinating Center, who provided an overview of data acquired across all subcontractor groups. Following her presentation, the meeting took the form of two sets of breakouts sessions and one additional plenary session. The breakout sessions were divided into four groups; the 15 prevention subcontractors split out by specific program (i.e., Screening and Brief Intervention, Project CHOICES, and P-CAP), and the eight diagnosis and intervention subcontractors. The first set of breakouts focused on client outcomes, including data. The second set of breakouts, again broken out by the specific program, concerned applying findings, data, and emerging science to sustainable practices; each session was headed by a different expert.

A panel discussion on developing a comprehensive FASD system of care moderated by Ms. Hensley occurred after lunch.

## American Indian/Alaskan Native/Native Hawaiian—Monday, April 30, 2012

The final Native Expert Panel meeting under the current contract opened with a blessing by Stephen Hill, Vice President of the American Indian Society of Washington, D.C. In addition to comments from SAMHSA and a review of action items from the December 2011 meeting, Candace Shelton, the FASD CFE's Senior Native American Specialist, and Mr. Dubovsky, the FASD CFE's FASD Specialist, provided updates on training and TA tasks. They noted that the FASD CFE has provided 25 trainings and conference presentations to 700 attendees in Indian Country between 2010 and 2012.

Kendra King Bowes, Project Director for Native American Management Services, Inc., provided a summation of the three Native Leaders Conferences sponsored by the FASD CFE. Katherine Cole, Health Research Analyst for the FASD CFE, provide an inventory of known FASD programs and practices in Native Communities. Ms. Kimner, the FASD CFE's Product Development Manager, provided an update on revisions to the Native Resource Kit and on other products currently under development by the FASD CFE. In addition, participants shared various stories from their experience in the field and Deborah Black provided an update from IHS. The panel then had a discussion focused next steps and recommendations for the group; they particularly focused on ways of sustaining the work of the panel should the FASD CFE not continue.

The meeting closed with a presentation by Ed Reily, Distinguished Professor from San Diego State University, who provided a broad overview of the latest FASD research.

## Self-Advocates with FASD in Action Network—Tuesday-Thursday, May 1-3, 2012

SAFA Network advocates and their support persons split their time between the BFSS conference plenary sessions and their own meeting track. Members played major roles in both the planning of the meeting and the delivery of presentations that included *Use of Person-First Language*, *Strategies and Tips for Trainers and Speakers*, and *How to Get and Keep a Job*. Support person John McAndrew and his brother Paul provided music in a session titled *Speaking from Experience: A Personal Story about FASD With Music*. The meeting agenda also included time for drafting the group's vision and mission statements, discussion of issues related to sustainability, and two opportunities for support persons to meet separately to discuss issues of importance to them. SAFA Network members also hosted displays during the Poster Session and Exhibit Display. SAFA Network member Morgan Fawcett, a Native American flute player, provided music at the opening of the Poster and Exhibit Display. The underlying premise for self-advocacy, as well as for the SAFA Network, is *Nothing about me without me*, a declaration of the individual's right to have a voice in his/her own care and in how he/she is perceived, approached, and delivered services by others. The SAFA Network is led by Coordinators Rob Wybrecht and Jasmine Suarez-O'Connor and Liaison Leigh Ann Davis of The Arc of the United States.

# Conclusion

## Action Steps

After every BFSS conference, FASD CFE staff follows specific action steps to analyze the recently completed conference. Steps include the following:

- Compile lessons learned from the planning process and suggestions from the meeting evaluations.
- Solicit feedback from the SAMHSA COTR and Alternate COTR.
- Hold a staff debriefing session on information collected from the BFSS 2012 conference and related meetings. For example, this year SAFA Network members noted that they would like to lead a break out session at the conference on how (and why) to incorporate individuals with an FASD into State FASD task forces and prevention activities.
- Update the FASD CFE's Web site with information from the conference, including the meeting summary, presentations, links to Web sites and videos, speaker biographies, photographs, and participant lists.

## Outcomes

Each BFSS conference is evaluated by participants to gather their thoughts on the agenda, the speakers, the site, and the usefulness of the information shared, and to elicit recommendations for the next event. In addition to formal evaluation findings (Appendix A, beginning on the following page), positive trends emerge each year. For 2012, these include:

- **High participation**—Attendance at this year's BFSS conference was up by 19 percent from last year's event. Generally good weather and the positive reputation of this conference in the field made for an all-time-high turnout.
- **Desire to Sustain Groups Established Under the Contract**—Not only do NAFSC, BMN, and the SAFA Network continue to grow, but each group is strongly committed to sustaining their work following the conclusion of the FASD CFE's contract; many of their discussion at this year's BFSS emphasized those interests. What's more, several members of the SAFA Network have established or are interested in establishing local chapters of the group. In addition, the FASD CFE has reached an agreement with MOFAS to sustain the Learning Communities established under the subcontractor initiative, meaning they will continue to collaborate ever after cessation of FASD CFE funding.
- **A Sense of a Tipping Point**—A major theme weaving itself through this year's conference was a sense that the topic of FASD is at or approaching a tipping point. A major factor contributing to this spirit was the conclusive nature of BFSS, with many presenters providing overviews of accomplishments attained over the last 5 years and plans for the future.

# APPENDIX A: CONFERENCE EVALUATION

## Introduction

The evaluation of the 2012 BFSS conference focused on determining the attendees' overall level of experience related to attributes of the meeting, such as quality and clarity, information sharing, networking opportunities, and applying lessons learned to work situations. In addition, attendees were asked to provide feedback on the usefulness of each of the sessions.

## Methods

An evaluation form was designed to elicit feedback from attendees. Evaluation forms were provided to all attendees and filled out and returned to FASD CFE staff at the end of the conference. Completed evaluation forms were checked for data accuracy, entered into the data system, and analyzed. Responses to close-ended questions were compiled to show frequencies of specific answers and a content analysis was performed for the open-ended responses.

## Evaluation Questionnaire

The questionnaire was designed to include both close-ended and open-ended questions. The first question was designed to get respondents' ratings on general aspects of the conference. The second question regarded the usefulness of the general and breakout sessions. The evaluation form follows as Appendix B.

Attendees were asked to respond to open-ended questions on the following topics:

- The most useful part of the conference;
- Plans to use what they learned at the conference in their work; and
- Suggested topics or speakers for future conferences.

## Evaluation Results

A total of 169 respondents submitted completed evaluation forms. Quantitative and qualitative results are presented below.

## Quantitative Results

Respondents' ratings of the conference overall, and of the sessions held during this event, are presented in Tables 1 and 2 below. The percentages of respondents shown in these tables are based on the actual numbers of those who answered a particular question, as shown in the last column of Table 1 and Table 2.

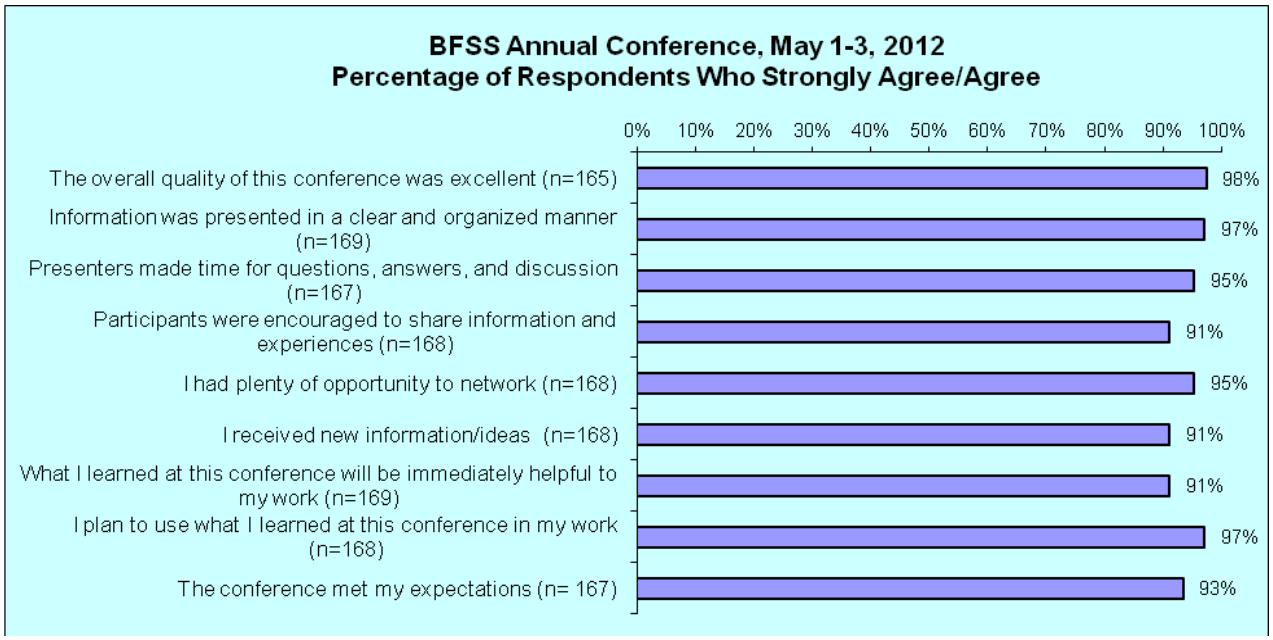
**Table 1—General Assessment of the Conference**

| Item | Strongly Disagree | Disagree | No Opinion | Agree | Strongly Agree | Total |
|---|---|---|---|---|---|---|
| The overall quality of this conference was excellent. | 1 (1%) | 0 (0%) | 3 (2%) | 71 (43%) | 90 (55%) | 165 (100%) |
| Information was presented in a clear and organized manner. | 1 (1%) | 3 (2%) | 1 (1%) | 78 (46%) | 86 (51%) | 169 (100%) |
| Presenters made time for questions, answers, and discussion. | 1 (1%) | 3 (2%) | 4 (2%) | 64 (38%) | 95 (57%) | 167 (100%) |

| Item | Strongly Disagree | Disagree | No Opinion | Agree | Strongly Agree | Total |
|---|---|---|---|---|---|---|
| Participants were encouraged to share information and experiences. | 1 (1%) | 2 (1%) | 12 (7%) | 55 (33%) | 98 (58%) | 168 (100%) |
| I had plenty of opportunity to network. | 1 (1%) | 3 (2%) | 4 (2%) | 71 (42%) | 89 (53%) | 168 (100%) |
| I received new information/ideas. | 1 (1%) | 2 (1%) | 5 (3%) | 53 (32%) | 107 (64%) | 168 (100%) |
| What I learned at this conference will be immediately helpful to my work. | 1 (1%) | 1 (1%) | 13 (8%) | 58 (34%) | 96 (57%) | 169 (100%) |
| I plan to use what I learned at this conference in my work. | 1 (1%) | 1 (1%) | 3 (2%) | 56 (33%) | 107 (64%) | 168 (100%) |
| The conference met my expectations. | 1 (1%) | 0 (0%) | 10 (6%) | 56 (33%) | 100 (60%) | 167 (100%) |

**Note: Due to rounding, sums may not add up to 100 percent.**

**Figure 1—General Assessment of the Conference**




As shown in Figure 1, respondents gave the conference a highly favorable assessment, with the vast majority (98 percent) rating it as excellent in quality and indicating that they planned to use what they learned in their work (97 percent). Almost all respondents felt that the information presented was clear and well organized (97 percent) and most agreed that presenters made time for questions, answers, and discussion (95 percent).

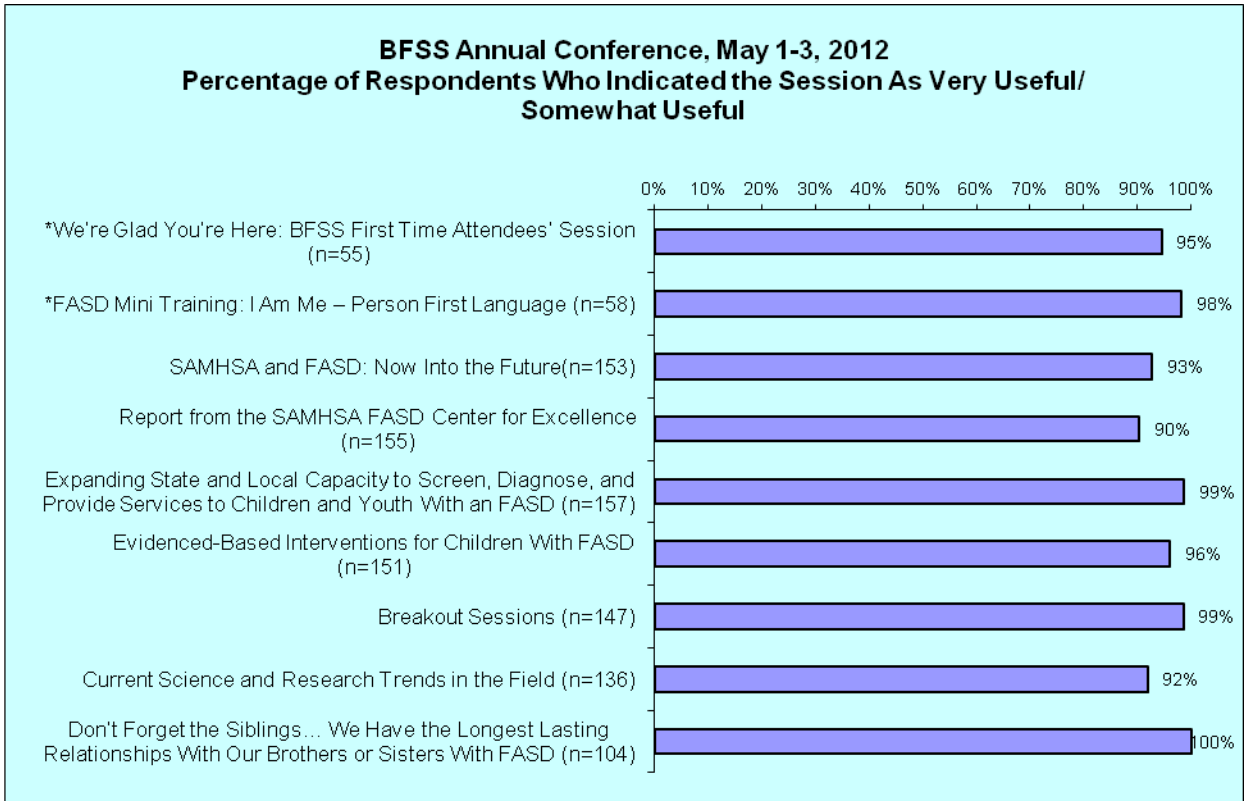
When comparing the rating of this conference to the 2011 BFSS Conference in Phoenix, AZ, the scores were a bit higher in some categories and a bit lower in other categories. Changes in ratings ranged from an increase of 4 percent (opportunity to network) to a decrease of 4 percent (presenters made time for questions and discussion).

## Table 2—Assessment of the Sessions

| Please circle the number that matches your answer. | Not at All Useful | Not Very Useful | Somewhat Useful | Very Useful | Total |
|---|---|---|---|---|---|
| We're Glad You're Here: BFSS First Time Attendees' Session* | 1 (2%) | 2 (4%) | 22 (40%) | 30 (55%) | 55 (100%) |
| FASD Mini Training: I Am Me—Person First Language* | 1 (2%) | 0 (0%) | 17 (29%) | 40 (69%) | 58 (100%) |
| SAMHSA and FASD: Now Into the Future | 0 (0%) | 11 (7%) | 63 (41%) | 79 (52%) | 153 (100%) |
| Report from the FASD Center for Excellence | 1 (1%) | 14 (9%) | 61 (39%) | 79 (51%) | 155 (100%) |
| Expanding State and Local Capacity to Screen, Diagnose, and Provide Services to Children and Youth With an FASD | 0 (0%) | 2 (1%) | 54 (34%) | 101 (64%) | 157 (100%) |
| Evidenced-Based Interventions for Children With FASD | 0 (0%) | 6 (4%) | 42 (28%) | 103 (68%) | 151 (100%) |
| Breakout Sessions | 0 (0%) | 2 (17%) | 29 (69%) | 116 (87%) | 147 (100%) |
| Current Science and Research Trends in the Field | 1 (1%) | 10 (6%) | 42 (31%) | 83 (61%) | 136 (100%) |
| Don't Forget the Siblings… We Have the Longest Lasting Relationships With Our Brothers or Sisters With FASD | 0 (0%) | 0 (0%) | 17 (16%) | 87 (84%) | 104 (100%) |

***Optional pre-conference sessions.**
**Note: Due to rounding, sums may not add up to 100 percent.**

## Figure 2—Assessment of the Sessions



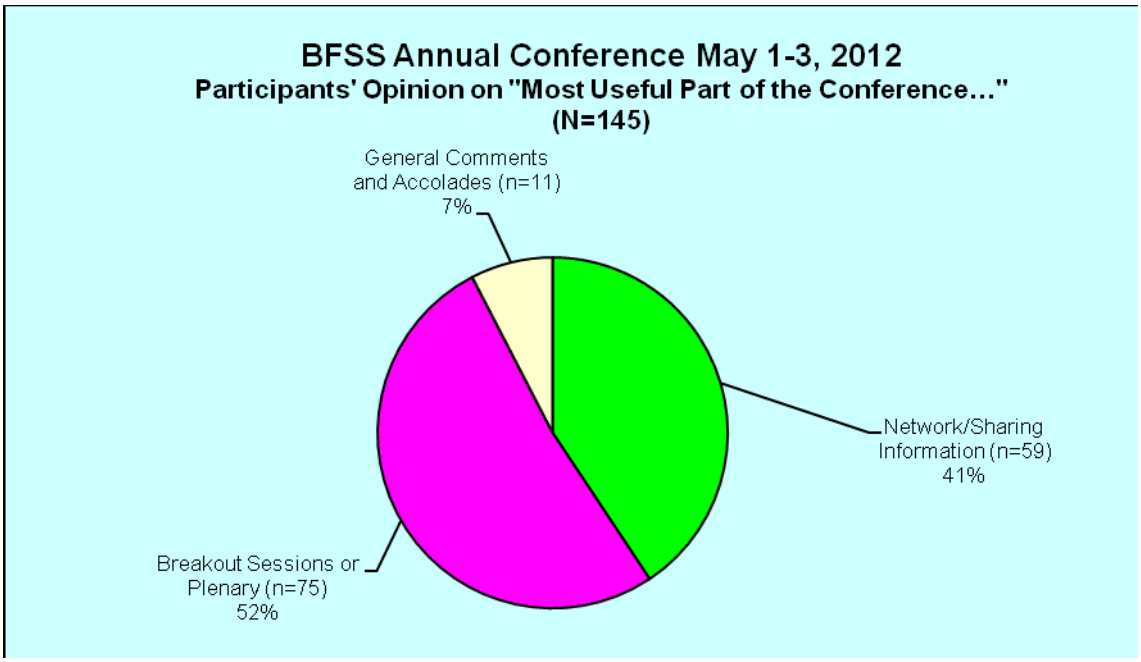

***Optional pre-conference sessions.***

As illustrated in Figure 2, the sessions that were rated as "very useful/somewhat useful" by the highest percentages of respondents were *Don't Forget the Siblings…We Have the Longest Lasting Relationships With Our Brothers or Sisters With FASD* (100 percent), *Expanding State and Local Capacity to Screen, Diagnose, and Provide Services to Children and Youth With an FASD* (99 percent), and the "Breakout Sessions" (99 percent).

## Qualitative Results

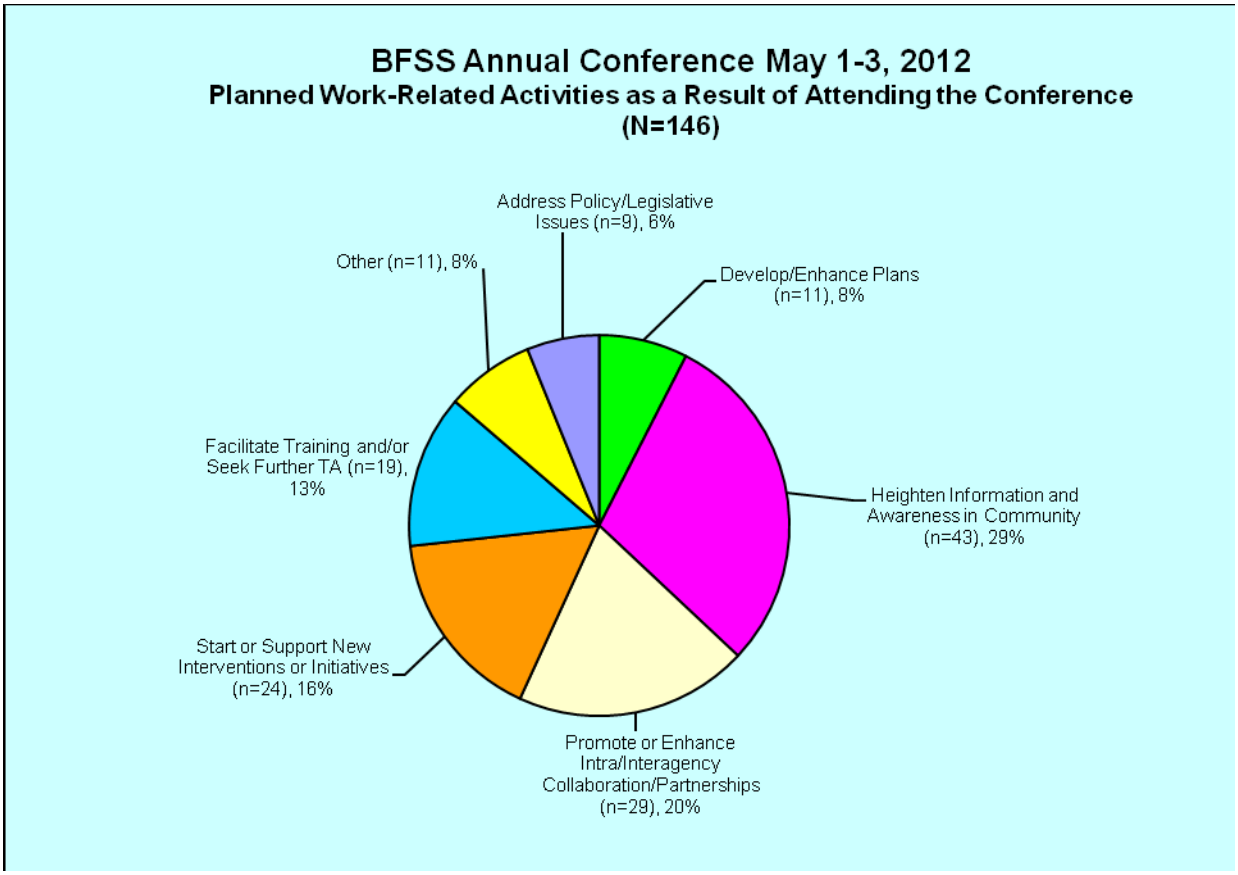
Respondents provided written comments about this conference to three open-ended questions. For each of the open-ended questions, responses were grouped under specific topic areas. The total number of responses within each topic area for each of the questions is represented in the pie charts on the following pages.

**Figure 3—Most Useful Part of the Conference**



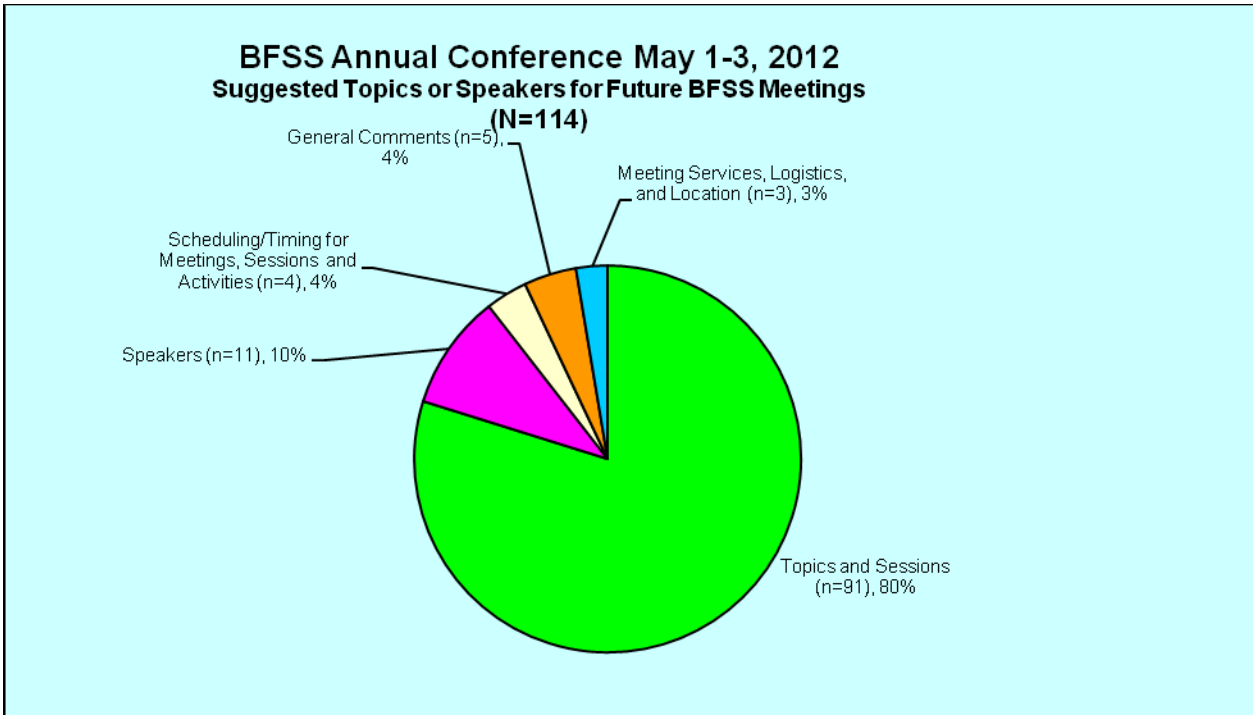

As presented in Figure 3, the majority (52 percent) of the responses indicate that participants found the breakout or plenary sessions to be the most useful. Forty-one percent of the responses indicated the networking and sharing information to be most useful.

**Figure 4—Respondents' Planned Work-Related Activities as a Result of Attending the Conference**




Among the 146 responses received to this question, the most frequently reported priorities were to heighten information and awareness in the community (29 percent).

**Figure 5—Suggested Topics or Speakers for Future BFSS Conferences**




Of the 114 responses for suggestions for topics or speakers for future BFSS conferences, the majority (80 percent), provided suggestions on new ideas for topics and sessions.

## Evaluation Conclusions

Evaluation results presented above indicate that this conference was a success. Significant findings from the quantitative and qualitative data presented in Tables 1 and 2 and responses to the open-ended questions are as follows:

- Overall, 98 percent of the respondents rated the quality of this conference as excellent, and 97 percent indicating that they planned to use what they learned in their work.
- The vast majority of respondents (97 percent) felt that the information presented was clear and well organized, and that presenters made time for questions, answers, and discussion (95 percent).
- The sessions viewed most useful were *Don't Forget the Siblings…We Have the Longest Lasting Relationships With Our Brothers or Sisters With FASD* (100 percent), *Expanding State and Local Capacity to Screen, Diagnose, and Provide Services to Children and Youth With an FASD* (99 percent), and the "Breakout Sessions" (99 percent).
- Fifty-two percent of the responses indicated that the breakout or plenary sessions were the most useful part of the conference.
- The most frequently reported work-related plans were to heighten information and awareness in the community (29 percent).
- The majority of the responses (80 percent), on topics/speakers for future conferences, were new ideas for topics and sessions.

## APPENDIX B: EVALUATION FORM

*Substance Abuse and Mental Health Services Administration*
*Center for Substance Abuse Prevention*
*Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence*

# Building FASD State Systems (BFSS) Conference

Hyatt Regency Crystal City at Reagan National Airport • Arlington, Virginia • May 1–3, 2012

## Capitalizing on Awareness: Bringing the FASD Message to the Forefront

### *EVALUATION FORM*

Date Completed: _____

Title/Position: _____

1. **Have you attended a BFSS meeting in the past?** Yes No

2. **To what extent do you agree with the following statements about this conference:**

| **Please circle the number that matches your answer.** | **Strongly Agree** | **Agree** | **No Opinion** | **Disagree** | **Strongly Disagree** |
|---|---|---|---|---|---|
| The overall quality of this conference was excellent. | 5 | 4 | 3 | 2 | 1 |
| Information was presented in a clear and organized manner. | 5 | 4 | 3 | 2 | 1 |
| Presenters made time for questions, answers, and discussion. | 5 | 4 | 3 | 2 | 1 |
| Participants were encouraged to share information and experiences. | 5 | 4 | 3 | 2 | 1 |
| I had plenty of opportunity to network. | 5 | 4 | 3 | 2 | 1 |
| I received new information/ideas. | 5 | 4 | 3 | 2 | 1 |
| What I learned at this conference will be immediately helpful to my work. | 5 | 4 | 3 | 2 | 1 |
| I plan to use what I learned at this conference in my work. | 5 | 4 | 3 | 2 | 1 |
| The conference met my expectations. | 5 | 4 | 3 | 2 | 1 |

**3. How useful were the following sessions:**

| Please circle the number that matches your answer. | Very Useful | Somewhat useful | Not Very Useful | Not at all useful | Attended Session (Circle Yes or No) |
|---|---|---|---|---|---|
| We're Glad You're Here: BFSS First-Time Attendees' Session | 4 | 3 | 2 | 1 | Yes No |
| FASD Mini-Training: I Am Me—Person-First Language | 4 | 3 | 2 | 1 | Yes No |
| SAMHSA and FASD: Now and Into the Future | 4 | 3 | 2 | 1 | Yes No |
| Report from the SAMHSA FASD Center for Excellence | 4 | 3 | 2 | 1 | Yes No |
| Expanding State and Local Capacity to Screen, Diagnose, and Provide Services to Children and Youth With an FASD | 4 | 3 | 2 | 1 | Yes No |
| Evidence-Based Interventions for Children With FASD | 4 | 3 | 2 | 1 | Yes No |
| Breakout Sessions | 4 | 3 | 2 | 1 | Yes No |
| Current Science and Research Trends in the Field | 4 | 3 | 2 | 1 | Yes No |
| Don't Forget the Siblings…We Have the Longest Lasting Relationship With Our Brothers or Sisters With FASD | 4 | 3 | 2 | 1 | Yes No |

**4. What was the most useful part of this conference for you? Please explain.**

**5. What are one or two things you plan to do in your work, based on what you learned at this conference?**

**6. What topics or speakers would you suggest for future BFSS Conferences?**

***Thank you for your feedback. Please drop in the evaluation box.***