



Hope for Women in Recovery

Understanding and Addressing the Impact of Prenatal Alcohol Exposure

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SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence

Introduction

Nearly 40,000 babies are born each year with a range of birth defects known as fetal alcohol spectrum disorders (FASD). To address the problems related to FASD, Congress authorized the Substance Abuse and Mental Health Services Administration (SAMHSA), under the Children's Health Act of 2000, to create an FASD Center for Excellence. The Center has six legislative mandates, with one of the mandates directing SAMHSA to develop innovative ways to prevent alcohol abuse among women in their childbearing years.

In 2003, as part of its efforts to address the legislative mandate regarding prevention of alcohol abuse, SAMHSA's FASD Center convened women in recovery summits, hosted by the National Organization on Fetal Alcohol Syndrome (NOFAS). The first-ever summit was held in 2003 in Baltimore, Maryland. In 2004, the Center followed up with a second summit in Phoenix, Arizona, specifically for Native American women. The third summit was convened in 2005 in Raleigh, North Carolina.

Each summit is designed to educate two target audiences: women of childbearing age in recovery and substance abuse treatment center staff. On the first day, attendees learn about the effects of prenatal alcohol exposure and the needs of children with an FASD. At the end of the day, a town hall meeting is convened to allow attendees to testify to policymakers and government staff persons about their personal experience with FASD. On the second day, policymakers come together to learn about FASD and how it affected individuals within their State.

About 150 people attended the first day of the summit, including women from North Carolina treatment centers, treatment center counselors, and staff from NOFAS and the FASD Center. About 90 people attended the second day, including State policymakers and government officials. Participants were greeted by Samantha Edwards from Senator Dole's office; Flo Stein, vice president of the National Association of State Alcohol and Drug Abuse Directors; and Jessie Taliaferro of the Raleigh City Council. In addition, several agency staff from North Carolina shared a Governor's proclamation declaring July 21 FASD Awareness Day in North Carolina.

Wednesday, July 20, 2005

Welcome

Ammie Bonsu, MPH, Project Officer, SAMHSA FASD Center for Excellence, Center for Substance Abuse Prevention (CSAP)

Ms. Bonsu welcomed everyone and said that she was pleased to be there. It was an honor to be among warrior women. She recognized NOFAS's work in organizing the meeting and acknowledged the efforts of Starleen Scott Robbins of North Carolina.

About 40,000 babies are born each year with an FASD. Congress authorized the FASD Center for Excellence in the Children's Health Act of 2000 and included a mandate to prevent alcohol use among women of childbearing age. SAMHSA launched the Center in 2001. At the many town



hall meetings the Center convened, staff learned that women in recovery needed information on FASD. It is also important to raise knowledge and awareness among men and get partners involved.

The first summit for women in recovery was held in Baltimore in 2003, the second in Phoenix in 2004 for a primarily Native American audience, and the third in Raleigh in 2005. Ms. Bonsu encouraged the women to network and support each other. She said that their future held opportunities for friendship, careers, and healthy children. They should embrace these opportunities.

Summit Overview

Gayl Anglin, PhD, Deputy Project Director, SAMHSA FASD Center for Excellence

Dr. Anglin explained that the goal of the summit was to increase knowledge and awareness of FASD among women in recovery and their counselors. She then reviewed the agenda.

Alcohol and Women: What You Need to Know

Linda Hammock, Master's in Counseling, LLPC, CCAS, Family Wellness Recovery Services, Hope Meadow

Ms. Hammock is an addiction professional, recovering alcoholic, and single mother. She has worked in the addiction field for 20 years. She identifies with her clients' courage and challenges. She was a functioning alcoholic with marketable skills during her recovery, which helped.

Ms. Hammock noted that 10 percent of women are vulnerable to alcoholism, but the statistics are unclear. Alcoholism is a progressive disease that grows over time. A woman may not realize she has an alcohol problem for 15 years. Society tends to recognize only severe problems.



Alcoholism is a genetic disorder and some people have a predisposition. Environmental and emotional factors contribute, but alcoholism is not a choice. Some women can go through their childbearing years without knowing they have alcoholism. In Ms. Hammock's case, she stopped drinking when she learned she was pregnant but she drank before she knew. Her son has some signs of fetal alcohol syndrome (FAS), and raising him was a challenge to her recovery.

Women respond to alcohol differently. They have more fat cells, which affects how they metabolize and break down alcohol. Hormones affect cravings and the progression of the disease, which affects efforts to recover. For example, emotions during the menstrual cycle can be hard to manage during early recovery.



Women also have more co-occurring disorders that contribute to alcoholism. Polysubstance use and drinking in isolation lead to denial. Women tend to choose substance-using partners and get victimized. Women also are discouraged from getting treatment because they might have to leave their children. Thus, women become dependent on partners, social services, and family.

Alcohol abuse is often a response to trauma. Many losses may be involved, such as miscarriages, sexually transmitted diseases, and divorces. Women develop low self-esteem and drink to self-medicate. The societal message about alcoholic women becomes internalized.

It is hard for alcoholic women to form relationships with women due to competition for men. Women need to learn that they can protect each other. They need to network to learn to help each other. The structure in recovery needs to be balanced with empowerment. Women need to focus on strengths and challenge beliefs that keep them victimized. They need to be validated for balancing recovery with family life. Finally, recovery programs need to be personalized and suited to the individual woman.

Women need to focus on strengths and challenge beliefs that keep them victimized.

Alcohol and Pregnancy: Owning Your Warrior

Kathleen Tavenner Mitchell, MHS, LCADC, NOFAS Vice President and Spokesperson

Ms. Mitchell said that the summit was a real opportunity. “Some of you will make a decision to get your life in order and some of you will go the path of addiction. You have a choice.” She said the summit was a chance to network and help each other “so that we don’t have to live like this anymore.” She said that in the room that day were some of the strongest women in North Carolina.

Ms. Mitchell told the women that they were surrounded by love but “it is up to you to own your warrior and find your strength.” She said that we need to learn how to engage people with our stories. Ms. Mitchell noted that there were unbelievable women there who had survived some incredible things and were making a difference nationally.

Ms. Mitchell works with NOFAS, a nonprofit that educates about FASD and provides information and links to resources. One of the most effective ways to get the message out is the media, such as the episode of “Law & Order: Special Victims Unit” that dealt with drinking during pregnancy. The episode featured a mock NOFAS office.

FASD is an umbrella term for all alcohol-related disorders, such as fetal alcohol syndrome, alcohol-related neurodevelopmental disorder (ARND), and partial FAS. Maternal alcohol use is the leading known cause of mental retardation and a leading cause of birth defects and learning disabilities. The disabilities are lifelong, resulting from the brain not forming properly.

Ms. Mitchell has been clean and sober for over 21 years. She grew up in an alcoholic family. Both her grandfathers, her aunts and uncles, and her father had alcoholism. She did not know about





alcoholism; she just thought her father got ugly when he drank. Her father sometimes hurt her mother physically. Ms. Mitchell went into caregiving mode to protect her little sisters. She tried to stop her father but he was too big. The violence took its toll on her and she had trouble in school.

Ms. Mitchell said that her decisionmaker was broken. She was proud of her drinking because it was something she was good at. She got no reaction from her mother regarding her schoolwork, good or bad. She was a hostage to her father's drinking, and she partied a lot. She drank, used drugs, and had sex. She tried anything, but heroin was

her drug of choice. Ms. Mitchell got pregnant in 10th grade and married the father. He had used drugs and had a criminal record. Ms. Mitchell gave up drugs but drank wine. She did not realize that alcohol was a drug.

At 18, she was on welfare, her husband was in jail for drug dealing, she was homeless, and she had two children. Her husband got out of jail and they had a third child. Ms. Mitchell broke up with her husband and got a job at a bar. She liked the job because she could drink. She got involved with a man who gave her drugs and she married him. He was abusive and could not hold a job. She ran the streets with him and neglected her children. She said that sharing her story is a gift so that others won't have to go through what she did.

She got pregnant again and thought it would help her get her life together. She gave birth 2 months prematurely to a boy named Matthew. He died the day he was born. She left the hospital and went out and drank and drugged. She got pregnant again a year and a half later. She was on methadone maintenance but the program never told her not to drink. She left her husband and moved to the suburbs. She gave birth to a girl and got off methadone. She got her children into school but was still drinking. At 3 months, the baby girl, Keisha, died. Ms. Mitchell believes that Matthew and Keisha's deaths were related to alcohol, which can lead to infant death.

Shortly before Keisha died, Ms. Mitchell's father got sober. He took her children and told her to get to treatment. She fought him. He had the children for a year and a half before she went into treatment. She entered a therapeutic community for almost a year and a 12 step program. She met a man in AA, dated him for 7 years, married him, and earned her master's degree. At a conference, she learned about crack babies and saw photos that looked like her daughter Karli. She looked up information on fetal alcohol syndrome and had Karli diagnosed at Georgetown Hospital. Karli had been misdiagnosed until she was 16. There were years of frustration and misdiagnoses, thinking that Karli was not trying her best and that she would grow out of it.

As an aside, Ms. Mitchell noted that her father was sober the last 20 years of his life and became his true self. She said to give yourself time in recovery to become your true self. She also said, “I am a really good mother. You guys are really good mothers.”

She described her grief and how she blamed herself for Karli’s FAS, but alcoholism was a disease. She wondered why she did not get treatment sooner. Then she went into warrior mode of do or die. She learned to see life as a circle, to meet herself, to enjoy life. She bloomed and looked for spiritual healing. She learned that Karli was her spiritual teacher. Karli is good to others and cannot be bad to anyone. Now Ms. Mitchell feels blessed to have Karli.

Alcohol and Pregnancy: Effects on the Fetus

Mary DeJoseph, DO, New Jersey FAS Task Force Member

Dr. DeJoseph described herself as an osteopath and a warrior mom (birth mother). She said the only safe alcohol during pregnancy is no alcohol. Commonly abused substances include heroin, marijuana, cocaine, alcohol, and tobacco. The most dangerous are alcohol and tobacco, the only two that are legal. Dr. DeJoseph noted that we have known about the danger of alcohol to a fetus for centuries.

Dr. DeJoseph noted that all alcohol is harmful. The amount of alcohol in different kinds of drinks is the same. A standard drink is 12 ounces of beer, 5 ounces of wine, or 1-1/2 ounces of liquor.

It is important to screen for alcohol use because up to 10 percent of women admit alcohol use during pregnancy. The actual number is probably higher. FASD costs billions of dollars. FAS is the number one cause of preventable mental retardation.

FAS has clear criteria for a diagnosis: facial features (small eyes, smooth philtrum, thin upper lip), growth deficiency, and brain damage. Maternal history of alcohol use does not have to be confirmed. The facial features develop at 21 to 27 days’ gestation, before a woman may know that she is pregnant.



FASD is not a clinical diagnosis. It is an umbrella term. CDC released a consensus definition of the term in July 2004. FASD occurs in all races and socioeconomic groups. Some groups (e.g., South African, some American Indian/Alaska Native tribes) have higher rates. About 10 percent of alcohol-abusing women will have a child with FAS and 30 to 40 percent will have a child with an FASD.



When a pregnant woman takes a drink, so does her baby. Alcohol affects the woman and the fetus. Alcohol passes through the placenta and causes the blood alcohol concentration (BAC) in fetus to equal or exceed that of the mother. The fetus's liver cannot metabolize alcohol, so the BAC stays higher longer. One or two drinks can significantly decrease fetal breathing and movement.

Most organs are formed by 8 weeks and physical defects can occur in the first trimester. Organ function develops during the second trimester. There are constant changes during pregnancy. Effects vary by amount and timing of alcohol consumption, but the brain is affected the entire time.

Women are born with all the eggs that they will ever have and alcohol can damage eggs. Alcohol-affected sperm is less likely to fertilize an egg, but there are no cases of FAS where only the father drank. The real role of men in preventing FASD is to help women stay sober.

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Dr. DeJoseph reviewed fetal development and the role of alcohol. The first week or two is the preimplantation stage. The embryo is not vulnerable to alcohol. However, bleeding can take place during implantation. A woman might think she is having a light period and not know that she is pregnant.

Cell development can be affected by alcohol. Errors in cell development can be repaired if drinking stops. Nothing is definite. Some women drink and have healthy babies and some binge a couple times and have profoundly affected children. For example, the brain of a baby with FAS is smaller and may be missing tissue connecting the two hemispheres. The amount of alcohol, use of other drugs, smoking, and mental health issues such as depression are factors that can affect whether an FASD occurs. Other factors can affect a child's development besides alcohol, such as environment and school.

Dr. DeJoseph reviewed signs and symptoms that can be identified when seeking a diagnosis. Problems in people with an FASD include poor decisions, trouble handling money, and a tendency to hang out with the wrong people. She said that it is like being drunk but does not go away. "We get sober the next day. Kids with FASD still have problems." Management of an FASD includes person-centered care, mental health treatment, special education, substance abuse treatment, and health care. Sometimes the justice system is involved.

Dr. DeJoseph shared her background. She had a history of alcoholism in her family. She was an honors student but drank and prostituted herself. She was sober during her first pregnancy. She drank during her second pregnancy but did not know that she was pregnant. Child Protective Services got involved and her children were away from her for a while. A life-threatening illness led to her getting sober. She relapsed after she got out of a wheelchair, and she walked to the



liquor store. She got into a halfway house and learned that she was pregnant. After she had her daughter, she learned that she had cancer. As she got sober, she learned to be a sober wife and mother.

Her middle child was diagnosed with FAS at age 11. She was overcome with shame and grief. She went to the FASD Center's summit in Baltimore and met other warrior moms and got support. She talked to her son about FAS and her drinking during pregnancy. She hoped that her son could forgive her. He said that it was okay and he still loved her. Thus, she learned to forgive herself. Dr. DeJoseph described the healing triad: shame/anger, grief, and forgiveness.

If the Eyes Have No Tears, the Soul Has No Rainbow

Julie Gelo, Executive Director, NOFAS Washington

Ms. Gelo said that she came into FASD through the back door. She and her husband moved to Washington and became licensed foster parents. She has three grown biologic children, three stepchildren (two are grown and one is deceased), four adopted children who are Native American, and guardianship of three children. The seven youngest children all have an FASD. She learned about FASD when taking the children to be assessed and diagnosed. She began thinking about her drinking and her biologic children's problems. She took her oldest birth child for a diagnosis, and at 25, her daughter Faith was diagnosed with FAS.

Some of her children have the classic facial features of FAS. Some children do not have the FAS features that provide a clue that they need help. All of Ms. Gelo's children are different in terms of their behavior, but all will need services for the rest of their lives. For example, Tessa has an IQ of 110 but virtually no working memory and she does not understand time and money. Brandan has an IQ of 59 and will need a caregiver for the rest of his life.



Ms. Gelo summarized the stages of development. She noted that every child is unique but these are things a parent or caregiver might see. Infants may have sleep disorders, feeding problems, health concerns (e.g., ear infections), over- or underresponse to external stimuli, and delayed development. They may need routines and consistency (e.g., a set feeding and nap schedule). Brandan had feeding problems and could not crawl at 12 months. He received a lot of services and walked with an orthopedic walker at 24 months. He still has feeding problems at 10 years.

Toddlers may have motor delays, impulsivity and distractibility (more than typical), hyperactivity, speech delays, and sensory defensiveness. School age children may have trouble staying on task, social communication problems, boundary issues, poor peer interactions, academic concerns, and handwriting concerns. They often need classroom modifications.

Children with an FASD need outward cues to link cause and effect. If Mom says “ouch” when hit with a toy, Brandan will apologize.

During puberty, youth with an FASD exhibit defiance beyond the norm, do not understand cause and effect, have hygiene issues (beyond the norm), need a lot of reminders and cues, have trouble making and keeping friends, and are easily influenced by peers. Adolescents with an FASD are often cognitively, socially, and emotionally half their chronological age. Concerns include driving, sexuality, potential substance abuse, mental health issues, and future planning (jobs, finances, independent living).

In adulthood, issues include birth control, pregnancy, and substance abuse and mental health problems. Women with an FASD may be vulnerable to alcohol abuse and give birth to children with an FASD. Another possibility is that individuals with an FASD will have children who are higher functioning than their parents. Adolescents and adults with an FASD want to know why life is such a struggle. They are usually relieved to learn that the problem is an FASD.

Strategies That Help Individuals With an FASD

Diane Malbin, MSW, Clinical Social Worker, Executive Director, NOFAS Oregon/FASCETS

Ms. Malbin is the birth mother of an adult with an FASD. She opened with a brain visualization exercise. She asked participants to think of everything their brain had to do that morning. She noted tasks such as waking up, getting ready, and paying attention at the meeting. She then talked about the difficulties in persons with an FASD.

People with an FASD can compensate for the damage but it cannot be reversed. It is important to be aware of how differently people’s brains work. There is no such thing as a “normal” brain.

Alcohol affects brain cells, structure, and function. An FASD can be viewed as a physical disability with behavioral symptoms. Alcohol affects birth weight, intellect, organs, and level of activity (e.g., hyperactivity). Other substances affect some, but not all, of these areas.

Primary behavior problems reflect underlying structural problems in the brain. Symptoms may include memory problems, gaps or disconnections (e.g., told not to hit in the classroom, the child hits in the hall), slow auditory pace (takes longer to respond), dysmaturity (acts young for age), and difficulty predicting outcomes. Strengths may include visual, kinesthetic, artistic, musical, creative, and relational abilities, as well as a determined and willing nature.

Secondary behaviors develop over time due to a poor fit between the person and the environment. The disorganized brain has to work harder, which can cause anxiety, anger,



isolation, and depression. We need to provide accommodations for FASD like we do with other disabilities. We also need to redefine behaviors from won't to can't, from problem person to person with problems. In addition, we need to help adolescents learn to advocate for themselves and we need to provide support.

Examples of poor fit include teaching by talking to a visual learner, using abstract concepts with a concrete thinker, and telling someone who is young for his or her age to act age appropriately. A good fit would be using visual cues with a visual learner, giving a person with slower processing more time, and providing support. Ms. Malbin talked about a child named Fred who was 7-1/2. He had multiple diagnoses and multiple interventions. They learned that he functioned like a competent 3-year-old. The teacher modified his work so that he could finish in the time given and Fred's behavior improved.

Ms. Malbin concluded by noting that a neuropsychological evaluation could help identify issues related to brain function. She also noted the need for a multidisciplinary diagnostic team.

Stories of Recovery and Hope: Surviving the Grief

Moderator: Marcy Ten Eyck, Washington

Ms. Ten Eyck is a warrior mom. She said that most of the warrior moms found out about alcohol's effects on our children a long time ago and went through loss and grief. She talked about her own experience.

Ms. Ten Eyck came from a "perfect family." She got good grades until college, when she became overwhelmed. She became severely depressed and turned to alcohol. After college, she married an alcoholic. They were married 20 years. He is still drinking.

When Ms. Ten Eyck got pregnant, she was told to have a cocktail every night to relax and prevent miscarriage. But for her a cocktail usually was much larger than a typical drink. Her child had low birth weight. Her second child was premature with low birth weight. When Sidney, her second child, was in fifth or sixth grade, Ms. Ten Eyck realized that she was different and seemed on the fringes. Ms. Ten Eyck later learned about FAS.

When Sidney was 14, the school counselor recommended testing for learning disabilities. The school would not pay for testing, so they went to the University of Washington. Sidney was evaluated by Sterling Clarren, who diagnosed FAS. Sidney went on to graduate high school. She is now married and living in Italy.

Peggy Combs, California

Ms. Combs came from a nice, middle class family. She was in the Girl Scouts and got good grades. She started drinking and using drugs in eighth grade. She later moved to California and got a job. She lost that job and went to work as a bartender. She drank at work and partied at



night. She found out she was pregnant when she was 4 months along. She tried to stop drinking but had trouble. She never mentioned her alcohol use during her prenatal care.

Ms. Combs' daughter had delays, so she got her evaluated and she was diagnosed with FAS. Ms. Combs did not get into recovery until her daughter was 12. Tracy will never drive and cannot read. Ms. Combs told her why she has problems and that she would not hurt her if she had it to do over. Tracy said, "I know." Tracy is happy and substance free and has high self-esteem. Ms. Combs considers her a successful adult, which was Ms. Combs' number one goal as a parent.



Drema Jones, North Carolina

Ms. Jones had come off a binge when she learned of her most recent pregnancy. She stopped drinking, but her son had problems. She was once married to a drinker but stopped drinking when she got pregnant. One of her sons hurt her youngest child and was removed from the home. She later had her children evaluated and they have an FASD. Matthew, 12, does not learn from mistakes. Jeremy, 6, is hyperactive. Casey, 5, won awards for wrestling, which is one of his strengths.

Angelina Locklear-Taylor, North Carolina

Ms. Locklear-Taylor has been clean and sober for 17 years. She had a rural upbringing and came from a well-to-do family. She began drinking at 14 when her parents separated. She kept drinking even after a serious accident. She got pregnant at 21 and drank everyday. No doctor ever told her not to drink. She did not learn about FAS until 1996.



Angelina Locklear-Taylor and Drema Jones

Her son was held back in first grade, skipped school in middle school, and got in trouble with the law. She got pregnant with a second child in the 1980s, and he has no real problems. In January 1994, her older son got into a fight with his stepfather and killed him. He was convicted of first degree murder and sentenced to death. He is still on death row. He has never received any treatment. Currently they are trying to get his sentence overturned based on his FAS.



Circle of Hope: Warrior Moms Unite

Kathy Mitchell talked about strategies that helped. Once Karli was diagnosed, they focused on her strengths. Marcy Ten Eyck added that the diagnosis led her to shift from parenting bad kids to parenting kids with brain injury. The most helpful thing is structure. Her daughter's husband helps with that. In addition, when Sidney was in 9th grade, her teacher had her write about how she learned.

Julie Gelo emphasized the importance of environmental modifications, such as putting locks on the fence and not using a top sheet on the bed. She also said that it is important to understand education laws such as the Individuals With Disabilities Education Act and to understand FASD. In addition, it helps to know your own protective factors that will help you stay clean and sober, keep your sense of humor, reframe from won't to can't, and use person-first language ("child with FAS," not "FAS kid"). Diane Malbin said it is important to understand that bad behaviors are not deliberate. Educating others, being gentle to yourself, and advocating for your children to get their needs met also help.

Lisa Gladwell lost her parental rights because she did not have the capacity to maintain recovery but she has been sober for 3-1/2 years. Her recovery is a blessing. She has testified before Congress and is active in a New Jersey addiction-related group. She wants to be a lawyer to advocate for families and reunification. She said, "I am the best mother I can be. I am the best I can be today."

Peggy Combs goes to meetings and works the steps. She is learning to advocate for herself and her daughter. She is also teaching her daughter to self-advocate. Angelina Locklear-Taylor said that she is staying in touch with the lawyers and her son and being there for him. Naomi said that her 15-year-old son was recently diagnosed with an FASD. She has four other children and has been sober for 15 years. Nick was diagnosed with ADHD in fourth grade, so they got him some help. She noted that some things do not work, such as star charts. She said that building on strengths helps, such as language, and that her son responds to praise. She is learning to navigate the school system. Drema Jones said to get your child tested. It helps you understand how the child's brain works and what you can do to help, such as simplifying the room and using sign language.

Spiritual Closing

Cheryl Jill Plumage, BS, FAS Site Manager, Harlem, Montana

Ms. Plumage explained the rainbow family. All the colors are represented. There are four sacred colors (white, black, yellow, red) that represent the four directions and the four seasons. The most sacred is red, the color that goes through all of us and makes us the same. We may be different on the outside but inside we are the same.





She said that her son was born drunk in 1975. She was sent here to tell what happened to him so that maybe one baby will not be like him. She said that her son is not defective, he's holy.

Ms. Plumage smudged people using an eagle feather and let people hold the thunderbird stone. She prayed for strength, courage, wisdom, and love to go on this journey of sobriety.

Breakout Sessions

The video "Recovering Hope" was shown, and Julie Gelo helped participants prepare to testify at the town hall meeting that afternoon. She talked about the importance of sharing family stories and emphasized that there is no right or wrong. She also gave suggestions, such as staying calm, making eye contact, and projecting. Ms. Gelo said that testifying could bring up some difficult emotions and that was okay. Women who testified should tell their story the best way they could and not let others "rescue" them if it became difficult.

Thursday, July 21, 2005

Welcome and Overview

Gayl Anglin, Deputy Project Director, SAMHSA FASD Center for Excellence

The FASD Center was established by Congress in the Children's Health Act and launched in September 2001. The Center has six mandates. The summit relates to the prevention mandate.

The Center held town hall meetings in 14 States and Washington, DC, to determine available services. More than 200 family members, persons with an FASD, and professionals testified. Needs included respite care, professional education, and services. The Center has trained nearly 11,000 participants. FASD 101 is the most popular topic. The Center has also provided technical assistance to multiple States and has held trainings in more than 35 States, DC, Canada, Japan, and the United Kingdom. In addition, the FASD Center has 20 local, 10 State, and 5 juvenile court subcontractors integrating FASD prevention and treatment into their systems of care. One of the subcontracts is in North Carolina.

The summits are designed to increase information about FASD among women and policymakers. They have been very well received and helped launch efforts in Maryland and Arizona. The Center has also conducted three Building FASD State Systems meetings with participants from all 50 States, DC, and Puerto Rico. The meetings promoted information sharing and networking and led to the formation of the National Association of FASD State Coordinators, which has members from 14 States and Navajo Nation. NAFSC is working to

become independent of the FASD Center. One goal of the State subcontracts is to have an FASD State Coordinator in place.

The FASD Center is developing a database of practices being used in the United States and internationally. They are identifying criteria for promising practices and plan to disseminate the information. In addition, the Center is developing an American Indian/Alaska Native Initiative to address the higher rates of FASD in Native communities. The initial plans include regional meetings and women's summits.

The FASD Center is also developing several curricula. "Tools for Success" is for juvenile justice professionals. Pilot tests are planned in August. The Center is also drafting a curriculum for addiction professionals. The Center hopes to have FASD questions added to licensing exams for addictions professionals. FASD—The Basics is an online presentation available on the Center's Web site. In addition, an online course is being developed and continuing education units are planned.

The Center provides free publications and products through the National Clearinghouse for Alcohol and Drug Information and on the Web (fasdcenter.samhsa.gov). Products include a video, brochures, and fact sheets. Some can be put in doctors' offices. Several products are available in Spanish. The Center's Information Resource Center includes a Web database (fasdcenter.samhsa.gov), toll-free line (1-866-STOPFAS), e-mail address (fasdcenter@samhsa.gov), and library in Rockville, Maryland.

Why a Summit on Fetal Alcohol Spectrum Disorders (FASD)?

Kathleen Tavenner Mitchell, MHS, LCADC, Vice President, NOFAS

Experience shows that summits work. The model educates and supports women in recovery, professionals, and systems. It brings women and agencies together so that everyone is working together to create a better environment for prevention, diagnosis, and treatment.

FASD prevention and treatment should be a priority in addiction treatment. We need to identify children with an FASD to improve outcomes. Women with alcoholism are at high risk of having children with an FASD. Women who drank during one pregnancy are likely to drink during all pregnancies. They do not know that their children's problems are alcohol related. FASD is preventable, which is important since it has lifelong implications. We need to screen children for FASD when mothers are in treatment.

NOFAS is a nonprofit founded in 1990. It has affiliates in Alaska, California, Connecticut, Minnesota, Oregon, South Dakota, Washington, and the United Kingdom. Affiliates are planned for 2006 in Illinois and Tennessee. NOFAS has a clearinghouse, advocacy for families, public awareness efforts, curriculum development for medical and health professionals, and a Web site (www.nofas.org). They also have developed a peer education model for Native Americans and are



working on a K-12 curriculum project, women's summits, the curriculum for addiction professionals with the FASD Center, and the Circle of Hope birth mother network. They also have an earmark from the Health Resources and Services Administration for a community health center collaborative to look at risky drinking among women.

FASD is an umbrella term for all conditions related to prenatal alcohol exposure (e.g., FAS, partial FAS, ARND). There are about 40,000 new cases of FASD annually (1 in 100). This is more than muscular dystrophy, Down syndrome, and spina bifida combined. A recent study also showed greater risk of sudden infant death syndrome (SIDS) in babies born to pregnant women who binge drank in the first trimester. The relationship between an alcohol-exposed pregnancy and SIDS is being researched through the National Institutes of Health.

There are more new cases of FASD annually than muscular dystrophy, Down syndrome, and spina bifida combined.

Alcohol is one of the most damaging substances of abuse. It is worse than other substances, such as cocaine, heroin, and marijuana. Alcohol can cause permanent changes in the brain. Related behavior problems do not stem from foster care or a poor postnatal environment. The core issue is FASD, which can lead to mental health problems, attention deficits, and other disorders.

Prevention involves two patients, the child identified with an FASD and the birth mother. Alcohol use in pregnant women has decreased since 1995. However, binge and frequent drinking are still high. About 1 in 30 women drink at risky levels and half of pregnancies are unplanned. In 2005, the Surgeon General recommended that pregnant women and women trying to get pregnant stop drinking.

We need to train professionals to look at family history, tolerance, dependence, and organ damage to identify alcoholism in women. We need to identify problems early before they get worse. Addressing these problems can be difficult. Barriers to treatment include child care issues and denial. When women are in treatment, it is important to look at signs of possible alcohol use during pregnancy, such as miscarriages, stillbirths, and problems in their children.

Drinking and Pregnancy: Effects on the Fetus Last a Lifetime

Kathleen Sulik, PhD, University of North Carolina Department of Cell and Developmental Biology and Bowles Center for Alcohol Studies

FAS is recognized by the facial features: small head, small eyes and eye openings, smooth philtrum, and thin upper lip. Vision and hearing problems may be present as well. The eye opening is one of the first things clinicians look at. It reflects brain development. Problems seen in FAS include lower IQ, problems with decisionmaking, and memory deficits related to specific brain regions such as the corpus callosum, basal ganglia, and hippocampus.

The amount and timing of alcohol consumption affect development. The Surgeon General warns that women considering pregnancy should abstain. Alcohol can damage a fetus before the





pregnancy is recognized. An embryo is sensitive to damage about the time of the first missed period.

The fertilized egg implants around day 10. The brain and eyes develop from cells formed by day 17. The heart is beating by day 22. By 5 weeks, the developing mouth, eyes, and limbs are evident. The face forms from tissues surrounding the brain. The tissue between the developing nostrils forms the tip of the nose and philtrum and is affected by alcohol.

Mouse and human embryos are very similar. Researchers created FAS facial features by exposing mice embryos to alcohol. Alcohol can reduce the number of cells in the anterior and midline, which affects the forebrain and eyes. In addition, a fish model was used in a curriculum to teach alcohol effects. The developing fish exposed to alcohol have eyes too small and close together. They may look like one eye. Defects of the eyes can range from mild to severe.

Alcohol kills different brain cells at different times. These cells do not come back. Stem cells in the brain can generate new cells but alcohol can kill stem cells. This is a problem with earlier exposures to alcohol.

Addressing FASD in New York

Margo Berch Singer, MPA, New York State Office of Alcoholism and Substance Abuse Services (OASAS)

OASAS is New York's single State agency for substance abuse. OASAS recently received funding to include gambling, so the name may change. New York has the largest State system for prevention, treatment, and recovery and the largest substance abuse credentialed workforce in the country. It is hard to organize 1,000 treatment providers statewide.

New York has a State plan that focuses on FASD prevention. One size does not fit all, so other States may want to modify the model. New York also partners with the Federal Government to address FASD. Some States are more active and organized, such as Alaska and Washington.

Ms. Singer offered tips for addressing FASD prevention and treatment:

- Take baby steps. New York has a subcontract with the SAMHSA FASD Center and is making strides. They did what was easy first, such as creating a Web site (www.oasas.state.ny.us).
- Leverage existing resources.
- Collaborate. OASAS partnered with other agencies and with the American College of Obstetricians and Gynecologists (ACOG). New York had its first State meeting on FAS in 1999.

Unfortunately, there was no followup and the partnership ended. That is why it is important to build partnerships inside the State and outside the State. OASAS got organized and brought in new partners for a 2002 town hall meeting.

- Don't go it alone and don't depend on one person. You need an infrastructure. For example, NOFAS had Senator Daschle as a champion but now has a Congressional Caucus on FASD, which has 31 members.
- Conduct a needs assessment, which is a continuous process. Always assess needs and revisit your plan.
- Involve the press. Family stories attract the press. Also look at events, such as FASD Awareness Day.
- Maximize opportunities, such as working with an initiative to prevent underage drinking.
- Follow up on meetings to sustain momentum. Plan another meeting or do a mailing. In 2003, New York got a champion in FASD, a commissioner who had adopted a child with FAS. OASAS applied for a subcontract in 2004 and put together a proposal showing interest and dedication, as well as information on what was happening in the field. They also showed they had people who could pull it together, such as the Developmental Disabilities Council and ACOG. They were awarded the subcontract in November 2004 and had their first task force meeting in February 2005. They are focusing on prevention but hope to expand into services for people with an FASD. They are still building collaborative relationships with organizations, such as the Association for Licensed Midwives.
- Get people involved any way possible, such as putting them on committees. Be sure to involve families.
- Find ways to thank people, such as serving food, and be culturally sensitive.

Costs of FASD in North Carolina

Rick Harwood, Vice President, The Lewin Group

FAS cost \$5 billion in 2004, which is \$17 per capita or \$17,000 per case of FAS. We only have data for FAS, not for all fetal alcohol spectrum disorders. FASD occurs in about 1 in 100 births, or 40,000 per year. There are about 700 cases of FASD per year in North Carolina, of which 70 are FAS. There are about 4,800 people with FAS in North Carolina. FASD costs the State about \$87 million per year. Lifetime health costs for an individual are approximately \$843,000 and can be as high as \$3.7 million.

Cost estimates are based on cost of illness, which includes health care costs, lost productivity, and lost resources. The estimates presented are conservative. Some aspects of costs lack reliable data, such as mental health and criminal justice. One cost factor is the drinking rate among women of childbearing



age. The Behavioral Risk Factor Surveillance System looked at binge and heavy drinking among women 18-44. The rates were 14 percent in the United States and 8.6 percent in North Carolina.

Secondary disabilities include mental health problems, school problems, trouble with the law, and alcohol and drug problems. People with an FASD who do not have FAS facial features are less likely to be identified and to get services. Therefore, they may experience more problems and incur more costs.

Direct costs include the health system, social services, and the justice system. Indirect costs include mortality, morbidity, disability, and incarceration. National direct costs are \$3.14 billion for FAS and indirect costs are \$1.9 billion. Direct costs in North Carolina are \$54 million and indirect costs are \$33 million. Cost components include prenatal growth retardation (neonatal intensive care costs are estimated at \$24,000) and audiologic defects.

The most significant cost impact is brain dysfunction, which leads to special education, home care, and residential care. We need to educate policymakers, social services, and criminal justice professionals about costs. Direct costs per year per FAS case can equal \$10,000; in a worst case scenario, costs can be as high as \$50,000. Lost earnings can equal \$500,000.

An intervention to prevent FAS can be cost-effective at up to \$547,000 per case prevented. FAS is one of the most expensive birth defects. The Lewin Group has a report due in a month or two on the costs of FAS.

FASD: Effects on the Family

Moderator: Susan Robinson, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, Prevention and Early Intervention Team

Ms. Robinson said this was an opportunity to gain perspective on the impact of the caring, courage, and heart of families dealing with FASD. She said, “We all want healthy children, peace and stability in our homes, and changes that will help us be generous, giving, and loving.”

Sue Cortese

Ms. Cortese became the guardian of her cousin’s daughter when the girl was 12. Ms. Cortese was the only family available. She already had three sons ages 11, 13, and 15 and a 3-year-old daughter. In addition, two of her sons have Asperger syndrome and high functioning autism. Her cousin’s daughter has upended their lives. She has problems with shame because she has a normal IQ and is told she can do better.

Fortunately, the family has a trust fund available for her cousin’s daughter. They have spent about \$150,000 on care. They needed a nanny, because the girl was overly demanding toward Ms. Cortese. Ms. Cortese researched FAS and realized what the child’s issues were. Getting a diagnosis



was difficult. The developmental pediatrician was unfamiliar with specific FAS symptoms. Psychological testing revealed that she would never listen or make good judgments, so the clinician's attitude was why bother doing anything?

The Fullerton Genetics Center said that it was not FAS. Ms. Cortese provided information. They were sympathetic but lacked knowledge. Finally, she sat down with the child and went over her symptoms so that she would know she was not a bad child.



Sue Cortese, Christine and Dan Biddell, Angelina Locklear-Taylor, Diane Kienzle

Dan and Christine Biddell

The Biddells have four grown children and seven grandchildren, three of whom live with them. They have seven adopted children, five from Russia and two from Texas. They did not know about FASD but knew there was a history of maternal alcoholism and sexual abuse. Four of the children have FAS and one is suspected of having an FASD. The children blame their birth mother for their problems and their adoptive mother bears the brunt of their anger. Mr. Biddell wanted to thank the birth mothers for giving up their children.

The Biddells administer 27 doses of 11 medicines each day. It costs \$2,000 to \$2,500 per month to care for the children. They have to time the medication so that the children can sit for an hour at church. It may be the best hour of their day. One child rocks, and another beats his head against the wall. They become violent when their medication is off.

They home school the children and are seeing progress. They are working on the alphabet, colors, and sight words. They are teaching them to function, such as recognizing exit signs and the ladies' room. Mr. Biddell wonders what happens when parents are too old to care for their children. He said that we need to educate physicians and community members about FASD.

Angelina Locklear-Taylor

Ms. Locklear-Taylor is the birth mother of an adult, Robert, with an FASD. She did not know what was wrong. He was not diagnosed until he was in his 20s and in prison. Growing up, he was small for his age, had problems, and skipped school. He had a low IQ but the school never told her. He smoked marijuana and drank beer. She took him for a mental health evaluation but got



no recommendations because he was fine during the evaluation. She tried the court system but no programs were available. He finally got a counselor. He was doing well but fell in with some bad youth who got him into trouble.

Robert went downhill after his grandmother died. One night he got into a fight with his stepfather and shot him dead. Robert is now on death row. They are trying to get him off death row based on mental retardation. They have been waiting for a decision from the court for 18 months. Her younger son has forgiven his brother. He is in college now and doing well. If the death sentence is commuted, Robert will get life without parole. They may try for a new trial but they risk getting the death penalty again.

Diane Kienzle

Ms. Kienzle commended the birth mothers for being at the summit because they really care. She is an adoptive parent. She knew that her son's birth mother lived in a drug house with a lot of partying. Ms. Kienzle wanted to adopt her children but the birth mother would not let go. It took a while for the Kienzles to get their son. When they took him in, he was 18 months old and could barely walk. He could not talk or use utensils. He slept on the floor and could not sleep unless someone was touching him. They could not get him to sleep in a bed until he was 16 or 17.

Her son has had a lot of school and social problems, but he has not been involved in the juvenile justice system. He goes to a vocational rehabilitation course. The 3-month course is taking 6 to 9 months and he is frustrated.

Mrs. Kienzle used to hate her son's birth mother but now she pities her. She loves her son no matter what and will always be his advocate.

Questions and Answers

Someone asked about support groups for adoptive parents. There are not many in North Carolina. Ms. Cortese said that many children with an FASD are adopted and parents really need knowledge and support. Because of the stigma around adoption, there is a lack of knowledge in the schools about FASD. New York is using welfare funds for postadoption support, and New York held a statewide adoption conference. The only statewide activity in North Carolina is the foster parent association. Kelly Raiser referred to the NOFAS Web site for resources and help forming a support group. Someone else suggested Al-Anon, which is free and open to anyone whose life has been touched by a person with alcoholism.

Ms. Cortese mentioned that she sent her cousin's daughter to a boarding school for safety reasons. She said that families need to learn the possible impact of adopting a child with an FASD on younger siblings and the possibility of FASD when adopting. Ms. Robinson said that we are connecting the dots of FASD treatment and will continue to do so.



Keynote Address: A North Carolina Native's Passion for Prevention

Susan D. Rich, MD, MPH, Fellow, Department of Psychiatry, Children's National Medical Center, Washington, DC

Dr. Rich is a NOFAS board member and is excited to see FASD on the map in North Carolina. She has had mentors from the field of preconception health.

Dr. Rich noted that humans are distinguished from primates by executive functions, including higher level problem solving and abstract thinking. These functions can be stripped away by alcohol. She read *The Broken Cord* and was inspired to work on FASD prevention. She traveled to Native communities as a March of Dimes volunteer and taught about prenatal health. She developed a project to talk about preconception health and avoiding alcohol. Dr. Rich used her Iroquois background to write a booklet, *Planning for the Second Generation*, to distribute in Native areas.

She went to school for her master's in public health in 1994 and studied with Dr. Sulik. Her master's thesis looked at prenatal alcohol exposure as a risk factor for delinquency. She found that a chaotic life combined with cognitive disabilities put youth at risk. She also found that a disproportionate number of African American and Native American children had an FASD.

In rural areas, physicians lack awareness about FASD. Pediatricians are reluctant to diagnose due to stigma. Community and mental health workers are unfamiliar with treatment. In addition, FASD is not in the Diagnostic and Statistical Manual of Mental Disorders (DSM) used by clinicians.

In 1996, Dr. Rich went to medical school. She also worked on the Grace Court transitional program for women in recovery, which had an open house in 1998. The center was funded by a grant from the Department of Housing and Urban Development. Dr. Rich also participated in several other activities related to FASD prevention and treatment. She associate-produced a segment on "Good Morning America" on alcohol and pregnancy and worked with Dr. Sulik on a media and educational campaign. In addition, she created a video, "Planning for the 7th Generation" and expanded the program to Arizona and New Mexico with March of Dimes funding.

Dr. Rich noted that diagnosis is separate from treatment. She said that mental health professionals need to be able to diagnose an FASD. FASD needs to be in the DSM. She wrote an action paper and a workgroup is being formed to explore inclusion of FASD in the DSM.

Dr. Rich is now a fellow at Children's National Medical Center in Washington, DC. She is working in rotation with Dr. Paula Lockhart of Kennedy Krieger Institute on treatment. It is difficult to unravel environmental factors from cognitive problems. We need comprehensive



treatment and we need to know the strengths and weaknesses of the individual. Dr. Rich concluded by noting that her daughter, Brianna, is a reminder of the importance of a well-planned pregnancy.

Where To Go for Diagnostic and Other Services for FASD in North Carolina

Leslie Evans, MS, Director, FASD/Teratology Specialist, North Carolina Teratogen Information Service, Fullerton Genetics Center

Ms. Evans is the FASD Coordinator for North Carolina. She got interested in the issue when she heard about laws to jail pregnant women for drinking. She began by providing the toll-free number for the Pregnancy Exposure Riskline (1-800-532-6302). The line provides information on FASD and other substances. A Web site is also available (www.ncpregnancy.org).

*Pregnancy
Exposure
Riskline*

800-532-6302

There are many entry doors for services in North Carolina. Ms. Evans can help point people in the right direction. She noted the components of an FASD evaluation: growth, face, brain. A developmental and psychological assessment might be needed, as well as speech, language, occupational therapy, and physical therapy evaluations. FASD is not a diagnosis. It is an umbrella term. There are no specific tests or diagnostic criteria except for FAS.

North Carolina does not have any multidisciplinary FASD clinics with a geneticist, developmental pediatrician, and other needed specialists. The closest one is in Atlanta. In addition, North Carolina does not have an agreed on screening method or diagnostic checklist. However, CDC released diagnostic guidelines this summer. North Carolina has seven genetics centers and satellite clinics. The State Genetics Program is in Raleigh. The State has a major problem with screening and referral. Not many cases are identified.

The Fetal Alcohol Identification and Treatment Project is a subcontract the Fullerton Genetics Center has with the FASD Center that focuses on diagnosis and treatment in western North Carolina. They are training professionals on screening and the 4-digit diagnostic code. They are also training parent advocates and creating a parent support group.

To diagnose various fetal alcohol spectrum disorders, professionals on the project look at palpebral fissure length, use the lip-philtrum guide, and look at maternal history of alcohol use and family history (e.g., mental illness), social history, and family resemblance (e.g., thin lips). It is important to rule out other disorders. Developmental and psychological testing includes infant screening and screening by the Child Developmental Services Administration, school systems, and developmental pediatricians.



Resources include the North Carolina Family Health Resource Line for information on treatment for pregnant women (1-800-367-2229), the Alcohol and Drug Council of North Carolina, and Partnership for a Drug-Free North Carolina (www.drugfreenc.org). In addition, a free booklet is available on caring for a child with FAS (visit www.otispregnancy.org). The Family Support Network of North Carolina, the Fullerton Genetics Center, and the Family Support Network of Western North Carolina have a grant to provide materials. The Arc also has information.

Ms. Evans asked participants to contact her with information for the FASD resource guide she is compiling. She also suggested they join a coalition, become a field trainer, organize an FASD talk at their treatment centers, and become advocates.

FASD in North Carolina: Where We Are and Where We Are Going

Moderator: Flo Stein, Chief of Community Policy Management for the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS)

Ms. Stein opened the panel comments by saying that North Carolina has a lot of pieces they need to put together.

Janice Petersen, PhD, Prevention and Early Intervention Team, DMHDDSAS

Ms. Petersen works in prevention, including coalition building, education and training, advocacy, a hotline, family support, and the Baby Love program. She also is helping to develop the State plan for FASD.

Susan Robinson, Prevention and Early Intervention Team, DMHDDSAS

Ms. Robinson is working on the children's mental health plan. The team is looking at implementing evidence-based practices. They are also exploring interagency initiatives such as interagency coordinating council meetings and a State collaborative to implement services for families and children. In addition, they are working to integrate identification and referral of children with an FASD.

Starleen Scott Robbins, Coordinator of Women and Children's Services, Best Practice Team, DMHDDSAS

There are two policies regarding substance abuse treatment for women and children. The first is that the target population includes women with children, pregnant women, women trying to regain custody, and women with DFS involvement. This policy makes these women eligible for services. The second is that pregnant women have priority for treatment and receive interim services while waiting.

Several programs are available to women throughout North Carolina. The substance use specialist with the North Carolina Family Health Resource Line is funded through a contract



with the University of North Carolina. The number is 1-800-FORBABY. The specialist keeps track of treatment beds available in the State. In addition, in Greenville, there is a program for pregnant women and women with children under 12.

The North Carolina Perinatal and Maternal Substance Abuse Initiative provides residential treatment for pregnant women and women with children. North Carolina CASAWORKS for Families has treatment slots for women with children under 12. These are 12-month programs with aftercare. In addition, there are two transitional housing programs, Grace Court and a program in Moore County, for women in recovery and their children.

Kirstin Frescoln, Treatment Court Manager, Drug Treatment Court

Ms. Frescoln believes that many people in the court system are affected by prenatal alcohol exposure. Problems stem from lack of recognition of FASD. The adult treatment courts, family treatment courts, youth treatment courts, and mental health treatment courts are a mechanism to bring resources together.

David Mills, Department of Public Construction

Mr. Mills works in the division dealing with special education. No data are available on causes of disabilities. He teaches at North Carolina State and discusses FASD. He will be making information on FASD available to training centers and encouraging the inclusion of content on FASD in training. FASD issues also need to be included in individualized education plans (IEPs) and test accommodations. It can be hard to get families to IEP meetings, because some families are dysfunctional. Some schools are scheduling meetings outside the school to facilitate parents' attendance.

Sherri Britt, DPH, North Carolina Early Intervention

Early Intervention runs the infant and toddler program (see www.ncei.org). There are 18 children's developmental services agencies across the State conducting assessment and evaluation and making referrals for services. North Carolina is one of the few States that includes FAS in its "high risk established" category in determining eligibility for services.

Lizz Lyon, Lead Genetics Counselor, Genetics and Newborn Screening Unit, Division of Public Health

There are 20 satellite clinics across the State. Counselors often travel to meet with families. They also educate professionals and families about FASD. In addition, efforts are being made to increase access to care. Leslie Evans has Ms. Lyon's contact information if anyone has questions or needs help.



Angela Mullin, Social Work Consultant, Division of Public Health

Public Health offers families many preventive programs, such as the Child Services Coordination Program. This is a home visiting program for families with children birth to 5 who are at risk or have a disability. The Community Transition Coordinators conduct screening and referral for children birth to 5. In addition, some health departments offer psychological services. There is also a children with special health care needs hotline.

Mary Urzi, Director of Family Support Services, Wake County Human Services

All programs for children are part of her division, except for the public schools and early intervention. The county combines public health and social services, but services are not coordinated as well as would be expected. Many services are available but they are not easy to access. Frontline staff need to establish trust with women and learn to recognize FASD. Ms. Urzi said that she plans to start conversations about preconceptional health and training for line staff to work with women, recognize FASD, and coordinate services.

Evaluations and Closing

Flo Stein wrapped up by saying that North Carolina is committed to follow up on this meeting with a plan. Ideas for the plan include:

- Specialized training for perinatal workers and online courses for continuing education units
- Integration of FASD into public school curricula, such as questions on science tests
- Support for adoptive families
- Promotion of healthy transitions into the community for adults with an FASD
- Person-centered plans for the courts
- Identification of best practices for the care of persons with an FASD

Ms. Mitchell thanked everyone for participating.

