

September is FASD Awareness Month

Experts: No amount of alcohol safe during pregnancy

By Alison Laurio, News contributor

When Kathy Mitchell became pregnant with her daughter, Karli, no one knew that drinking alcohol could cause serious disorders that impact the baby — and the entire family — for the rest of their lives.

“I was like a Woodstock kid,” she said. “When I got pregnant, I stopped doing drugs. Everybody knew that could be bad for the baby. I drank wine. I didn’t even know.”

It wasn’t until 1973, the year Karli was born, that research first stated alcohol was causing birth defects, Mitchell said. She didn’t know about it right away, though, and by then, Karli had been diagnosed with cerebral palsy.

“When (Karli) was about 13 or 14, I was on the road to recovery and was taking classes to become a counselor when I stumbled on alcohol syndrome information,” Mitchell said. “Not having the correct diagnosis is more common than not. Doctors aren’t asking the questions about alcohol exposure. Most of the time, it is parents who figure it out.”

September is FASD Awareness Month, and the goal is to get the word out that fetal alcohol spectrum disorders — a range of lifelong disabilities — are completely preventable. The key message is simple: No alcohol is safe during pregnancy. It’s important because prenatal alcohol exposure can damage a developing brain at every stage of pregnancy.

While primary prevention is the foremost public health concern, those who work in the field also stress the importance of helping the affected persons and their families with treatment and support.

The National Organization on Fetal Alcohol Syndrome, or NOFAS, states on its website that it was started in 1990 by Patti Munter, who recognized the impacts of fetal alcohol syndrome among Sioux tribes across her state of South Dakota.

FASD Awareness Month was started in September 2015 as a national campaign to raise awareness of the risks of drinking alcohol during pregnancy and the needs of children and adults living with FASDs.

In 2014, the CDC launched a strategic cross-discipline partnership with NASW, the American Academy of Pediatrics, other leading medical organizations, and several universities to help prevent FASD.

The national social work discipline team, led by NASW-Texas member and clinical social worker Sandra Gonzalez, an instructor at Baylor College of Medicine, includes practitioners from Baylor, the University of Texas at Austin School of Social Work, and the University of Missouri.

Gonzalez told NASW News in April 2016 that the group’s goal was to build a multidisciplinary team approach through partnerships “to bridge the ‘research to practice’ gap in FASD prevention.”

Preventing FASD

Gonzalez, BS, MSSW, LCSW, and past president of NASW’s Tennessee Chapter, said she was drawn to the FASD issue for the same reason social work drew her in: “consideration of the unique needs of vulnerable and at-risk

groups, and not only the children and families of those with FASD, but ways we can prevent it.”

With the partnership with professional organizations and medical societies, “we’re trying to get information out to a nationwide audience about preventive services that can be delivered by various outreach agencies,” she said.

“Doctors — that’s something we are working on,” Gonzalez said. “We’re training physicians and their staff — from small practices to larger health systems — social workers and other health care providers.”

It includes providing information that women should not drink at all if they are planning to become pregnant, she said.

“Our training includes talking with health care professionals about the effects of prenatal alcohol exposure and encouraging them to discuss options for reducing the risk,” Gonzalez said. “Ultimately, we want to send the clear message that there is no safe time, no safe amount, and no safe type of alcohol during pregnancy.”

For some health professionals, talking to women about alcohol use during pregnancy can be difficult.

The training approach includes opportunities to engage in skill development and practice “to assist health care professionals in having these conversations and not feeling timid about it, not using stigmatizing language and leaving it open so patients know if they want to have conversations in the future, they can talk to their health care providers,” Gonzalez said.

Also in the works is a CDC website targeting various disciplines, but open to the public, that will have free online courses and other resources on prevention, identification, screening and intervention, and care of an individual with FASD, she said, adding that the courses should be launched in about a month on CDC.gov.

The role for social workers is to first know as much as they can about the effects of prenatal alcohol exposure, including FASD, Gonzalez said.

“Because of our incredibly diverse profession, we have a very unique role to play on the preven-

Alcohol use during pregnancy can lead to lifelong effects.

Up to **1 in 20** US school children may have FASDs.

People with FASDs can experience a mix of the following problems:

- Physical issues**
 - low birth weight and growth
 - problems with heart, kidneys, and other organs
 - damage to parts of the brain
- Behavioral and intellectual disabilities**
 - learning disabilities and low IQ
 - hyperactivity
 - difficulty with attention
 - poor ability to communicate in social situations
 - poor reasoning and judgment skills
- Lifelong issues with**
 - school and social skills
 - living independently
 - mental health
 - substance use
 - keeping a job
 - trouble with the law

Which leads to... These can lead to...

Drinking while pregnant costs the US \$5.5 billion (2010).

SOURCES: CDC Vital Signs, February 2016. American Journal of Preventive Medicine, November 2015.

What social workers can do to help prevent FASDs:

- Screen for alcohol use, perform brief interventions, and treat or make referrals for treatment of problem drinking.
- Screen sexually active teens for alcohol use and provide evidence-based interventions to reduce the risk of alcohol-exposed pregnancy.
- Use nonjudgmental language when advising pregnant women to stop drinking alcohol, and offer help if needed.
- Clear up misconceptions about alcohol use while pregnant: There is no known safe amount, no safe type.
- Communicate a consistent message: Alcohol and pregnancy don’t mix.

“Social workers are very important and effective members of teams. It’s important that a multidisciplinary approach is used,” she said. “Social workers can be a voice for ensuring that other professionals are talking to women about this key health issue. This is what social workers are good at — being advocates.”

Care Crucial

Leah Davies, BA, LMSW, is associate director of the Texas Office for the Prevention of Developmental Disabilities in Austin.

The NASW-Texas member and daughter of two social workers “felt called” to the profession after earning a bachelor’s degree and working as a school substitute.

“I felt like social work was the right way for me to continue effectively working with children and their families,” Davies said.

Drawn to populations facing complex problems, she said FASD can sometimes be difficult to detect.

“Some people have normal IQs,” Davies said. “They have no recognizable disability, yet their brain is different. Their ability to understand complex social situations is impaired. That people are able to be resilient in these situations to me is impressive and inspiring.”

People with FASD “vary enormously” from person to person, and their IQs range from low to normal to high, she said, adding that “nearly all benefit from early intervention.”

For children, it’s based on their individual needs and could include physical, occupational or speech therapy, she said, and mental health services always have an important role.

“Having FASD is tough,” Davies said. “If they’re young, educational services and support are recommended. Many schools across the country have great services so these children can thrive and learn.”

Those a bit older can be helped through employment support services where “sometimes just a small adjustment is needed,” Davies said.

Family services can be similar, and support services for them, like a caring or support group are always recommended.

“Beyond that is a really important component — advocacy,” she said. “The invisibility of FASD compounds it. A person with FASD often has an appearance that does not signify any special need, and some believe they just want to act that way. Unfortunately, it’s a common experience.”

A family has to explain to the world over and over what their loved one is experiencing, and they can “do an excellent job to help their loved one be understood by the community,” Davies said.

Long-term impacts are often misunderstood, she said. “While intervention and assistance and help can modify their experiences in life, people with FASD have a life-long impact. They’re going to

need support from families and the community their whole lives.”

By law, schools are required to provide support to those who learn differently, Davies said. School condition for youths with FASD “vary in a huge way from place to place,” she said, and it can be a challenge for individuals and families “depending on where they are and how willing the school is to provide support.”

“It comes down to how much time a family has to go to the school and explain, and do they have the words to explain what’s needed, and does the school have the ability to provide it.”

Social work can play a huge role because “we are made for this work,” she said. Social workers are charged by the Code of Ethics, they know what approaches will work, they see people with a focused lens and they have a duty to take stock of a person’s strengths and abilities.

“Social workers can serve in a prevention role, but beyond that, we can be excellent advocates and leaders,” Davies said.

In addition to prevention and advocacy, social workers can help fight stigma, support families and employ self-determination strategies. They also can work toward a cross-systems approach, which is “absolutely necessary for success,” she said. And, they can push for curriculum additions in social work schools.

“It’s a strength and a weakness for us, but social workers want to tackle all things that make people’s lives difficult, especially when it relates to social justice,” Davies said. “If we as social workers are more informed, we will be better at doing just that.”

Help for Moms

Mitchell earned an MHS and LCADC, and began public speaking and conducting FASD trainings when she was asked to speak at a Georgetown conference. There she caught the attention of then-U.S. Sen. Tom Daschle, D-S.D., whose 1997 legislative proposal resulted in Congress calling for the creation of a national task force on fetal alcohol syndrome in 1998.

Mitchell volunteered at NOFAS, then became a staff member, a board member and worked as a treatment counselor. She was a member of the national task force. But something kept bothering her. Then she realized what the missing piece was. Mitchell started Circle of Hope, a mentoring network for birth mothers, in 2004.

“I started the Circle of Hope because I realized that women don’t get a chance to stay sober because of their remorse, their guilt and the judgment of others,” she said. “They’ve been made a scapegoat — even by their own families.”

Through Circle of Hope, birth mothers are assisted in accessing treatment, like a 12-step recovery program or a treatment center. A social worker in her area is recommended.

“If a woman calls, we’re going to help and we’re going to provide a mentor for them,” Mitchell said. “Having a child with something like FASD — it’s like a scarlet letter. Everyone in the world will know. The stigma is huge.”