Transcription

Media File Name: FASD.mp3
Media File ID: 2592407
Media Duration: 1:01:34
Order Number: 1907302
Date Ordered: 2017-09-07

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Megan: Hello, everyone, and welcome to this "Ask the Expert" webinar, what are the long-term effects and impacts of fetal alcohol spectrum disorders, or FASD, on individuals and their families? I'm Megan Hiltner. I'm with the Healthy Start EPIC Center. We have approximately 60 minutes set aside for this webinar. It is being recorded, and the recording along with the transcript and slides will be posted to the EPIC Center's website following the webinar. This webinar is being held in observance of FASD Awareness Month, this month.

And before I turn it over to Ms. Dawn Levinson, who's the Behavioral Health Adviser to the Division of Healthy Start and Perinatal Services, who's gonna give a brief welcome and introduction, I have a couple more housekeeping announcements. We really want your participation today. So if at any point you have questions or comments, please chat them into the chat box, into the lower left corner of your screen. We will be taking questions only via the chatbox, and we will be getting to those questions following Ms. Kathy Mitchell's presentation today. Also, we want your feedback to this event, so please take a moment following the webinar to complete the survey that will pop up right after the webinar on your screen. Now I'm gonna turn it over to you, Ms. Dawn Levinson, for your opening and welcome. Dawn?

Dawn: Thank you, Megan. Good afternoon, everyone. This is Dawn Levinson with HRSA's Maternal and Child Health Bureau, and I am very pleased to be the division representative on today's webinar. So I will do the introduction of Ms. Mitchell. Ms. Kathy Tavenner Mitchell is the Vice President and National Spokesperson for the National Organization on Fetal Alcohol Syndrome or NOFAS, and a noted international speaker on fetal alcohol spectrum disorders, and women and addictions. She's a licensed clinical alcohol and drug counselor, has a Master's of Human Services degree, and has 25 years experience as a national educator, clinician, lecturer, and advocate.

She served on many expert panels, including the Special Committee of the World Health Organization, developing guidelines for the identification and management of substance use disorders in pregnancy, the US National Task Force on Fetal Alcohol Syndrome, the ACOG's special committee to develop a model of care for women with substance use disorders, and she continues to serve on the International Expert Planning Committee for the International Conference on FASD at the University of British Columbia. And on a personal note, having heard Kathy speak several times over the past several years, she is a powerful speaker, and I am honored to have her

address our Healthy Start grantee community today. So, Kathy, without further ado, I hand it over to you, and thank you so much for joining us today.

Kathy: Well, thank you, Dawn, and thank you to all the folks from the EPIC Center. I am absolutely thrilled to be with you this afternoon to talk about fetal alcohol spectrum disorders. So, today, some of the things that we're going to cover in a brief amount of time will...I wanna give you an overview about what can happen through the lifespan when someone has been exposed prenatally to alcohol. And we're also going to talk a little bit about strategies to reduce the stigma that's associated with FASD. And we're also gonna describe, or I am going to describe, some of the challenges and resiliency that come with families living with FASD.

So, again, I'm just really, really thrilled to be here with you guys today, and I thought we start with a question. So this is a poll question, something I'm just getting comfortable with, so I hope this goes off well. But I'd like you to answer this question. What recreational drug do you think causes the most long-term damage to the developing fetus? Is it, A, heroine? B, cocaine? C, alcohol? Or D, prescription opioids?

Megan: So just to add to Kathy's introduction here, you did a great job describing the poll. Folks, just click on one of the radio buttons next to one of the responses, the one that you think is correct. And, Kathy, when you're ready to close the poll and skip to the results, you just give me the word, and we'll close the poll. It looks like we have about 16 folks that have weighed in thus far.

Kathy: Okay. I guess let's do it. Close the poll.

Megan: Okay.

Kathy: Yay. 87.5% of you know that alcohol is actually the most damaging of all of the recreational substances that we just compared it to. And in 1996, as a matter of fact, the Institute of Medicine actually did a report stating that of all substances of abuse, that alcohol produces by far the most serious neurobehavioral effects in the fetus. So, again, that doesn't mean that those other drugs certainly are safe. It just means that alcohol is a teratogen, and I'm gonna talk about that in a few more slides, but it's the teratogen that causes cell death. So a teratogen is an agent that causes the cell not to form correctly or the cells to die, which results in permanent or lifelong effects on the developing brain and other

organs.

So in today's presentation, when you hear me say FASD, that's the acronym for fetal alcohol spectrum disorders. So that's an umbrella term I'm going to use that will include all of the disorders that fall under the umbrella that can occur from prenatal alcohol exposure. So the one that most of you are probably more familiar with is fetal alcohol syndrome, which is the rarest disorders seen from drinking in pregnancy. So fetal alcohol syndrome, for a person to have a diagnosis of FAS, a person would have to have specific facial features, some growth issues, and some brain issues. So, again, I'm going to review all of these in a few moments, so I just kind of run you through this briefly.

For partial FAS, that's for someone who doesn't have the full FAS, but someone would have basically brain issues with some notable facial issues, or growth issues, but not face and growth combined. And alcohol-related neural developmental disorder is certainly the most common disorder but the hardest one to diagnose. That's when someone has been exposed to alcohol but does not have any of the biomarkers. So they don't have facial features or growth, but they have a whole array of complex brain issues. And, again, you'll know what I'm talking about more by the end of this session.

And to further complicate the matter, now there's a new disorder listed in the DSM, known as neurodevelopmental disorder associated with prenatal alcohol exposure, NDPAE. NDPAE will eventually replace ARND one it's got its own code in the DSM. And to those of you that might have questions, because I know I'm throwing a lot of information at you very quickly, don't worry. Write them down, or you can send them, the question out, and I will get the questions at the end.

And I did wanna introduce you to NOFAS. We are now in our 28th year of operations. We're in Washington, D.C. We are really the most well-known and largest clearinghouse on FASD. There's our website, and if you go to our website, you can find our national resource directory. You can click under your state and find resources for diagnosis or treatment, and really whatever you're looking for. But I have to tell you also the reality of this situation is that resources can be scarce, but you can always contact me because... and I'm gonna give you my email at the end, and I will go do my very best to get the very best resource available for you in whatever you're looking for.

But anyway, you can get a lot of materials, and the one thing I would

recommend that you take some time to do is go to our YouTube site. We have interviewed almost 300 people with FASD, researchers, family members, adoptive families, birth families, clinicians. Really, you know, every expert that we can find, we try to interview, and so that you can really learn a lot through our videos, through our YouTube videos. And we also have webinars available, and we have them on a host of topic. So, certainly, if you wanna more, that's where you can find it.

And as Dawn had mentioned, this is FASD Month. And I just wanted to let you guys know actually, tomorrow is we're having a Twitter chat at 2 p.m. with the National Association of Social Workers and the ACOG, the American College of OB-GYNs, as well as AAP, the American Academy of Pediatricians, who's also joining us. The hashtag is #fasdchat. And we also have a webinar coming up on the 21st of Sept at 2 p.m. on the neuroscience of addiction, and we'll be welcoming the director of NIAAA for that. So I know that's a lot, but, boy, we have a lot going on all the time, but especially this month.

And one thing I would be remiss if I don't say this, you guys just rock. I love Healthy Start. I had worked with Healthy Start clinics in my area, and actually from around the nation. I have been a keynote at your national meeting in Washington, D.C., and what you guys do is the tough stuff. And I just want you to...to remind you that you are making difference. Don't ever think that you're not.

And I know that this resonates with you, this next slide here. We all know on this call that women aren't purposely damaging their child. This, you know, in the world of folks that don't know a lot about women who have seen better days, women who might be struggling with addictions or domestic violence, and really in need of support, you know, it's all too common for me to hear things like, "Oh, those women. Oh, you work with FASD? Oh, that must be so awful for you. I couldn't imagine working with women like that."

And, of course, it just flips my stomach. But we know the situation is that women don't know about how alcohol can affect their pregnancy. Women may say, "Well, as long as I'm not using heroin or cocaine, it's much better to drink a few beers." Women may be victims of domestic violence, and that's their only coping mechanism. Women may be struggling with addiction and maybe not even have treatment available to them, or not be able to leave their house for addiction...for treatment.

So there's lots of reasons. And a woman may not know she's pregnant

when she drinks. So there's lots of reasons that women drink during pregnancy, but to damage her own child is certainly not the reason. And when I talk a little bit further, stigma, really that is the core issue. If people hear fetal alcohol spectrum disorders, and immediately, the blame goes towards the mother, that this is a bad mother that did this on purpose.

And I really do think the stigma is also rooted in kind of the old medical model of how we used to think about alcoholism. Now I certainly know that alcoholism is not a term being used now. Alcohol use disorders is the term, or substance use disorders. But, you know, the old thinking was that people are doing that to themselves. They don't care. They must be shown the destruction of what they're doing to themselves, that they'll stop. Once withdrawal ends, if they continue to drink, then there's something really mentally wrong with them. Oh, well, they must just be trying to commit slow suicide. They just don't like themselves.

And certainly, you know, if you ask me why doctors don't intervene more with women that may be drinking, you know, I've certainly heard it said that doctors have told me, "Well, it's hard to intervene on somebody younger than you, or that drinks less than you do and tell them that they're an alcoholic." And so, hopefully, through education, one of the first things I tried to do in terms of combating the stigma, is to educate folks on why some people get addicted to alcohol and other drugs easier than others, or at all. Some people would just never become addicted to alcohol, even if they shut themselves in a closet and try to.

So it really is an issue of, it's a metabolic issue, of metabolism, of some genetic, certainly some environmental issues. But for most people that struggle with addiction, they don't need intensive psychiatric help. They don't need to put on...be prescribed a host of pills if they go to alcoholics Anonymous or another 12 step program or any kind of behavioral modification where they can learn not to drink successfully and be supported, that seems to do a much better job. So it is physiological. It's not psychological. It's not that people are crazy or weak-willed or disgusting.

And certainly women metabolize alcohol differently than men. So we have biological differences. Women have more fat and less fatty water than men. And as a result, they develop chronic disease more quickly than men do. They also have more denial and more fear and more defense mechanisms. So women are much more likely to defend their use or to minimize it. And they have a great deal of shame about

drinking. And, again, that has to do, I believe, a lot with the stigma that if a woman is drinking, it's different than a man. Women are seen as loose or slutty or tramp, where for a male, it maybe, hey, he's just a good old boy.

The women are much more likely to be victims of domestic violence. Most of their partners are going to be people that use. They combine alcohol with a whole array of other drugs, and are likely to be given prescription drugs. And they certainly have more social and economic differences that make it more difficult for them to get into treatment. And I always like to include a little bit of a story when I present, whether it's a webinar or whether it's live, because I think, for most of us, we remember stories and we learn better from stories. So I included a little case history, which is one I know very well because it happens to be my own. And I used to say that I got into this field by accident, but I really don't believe that there are accidents.

But anyway, so here is a picture of my children in 1977, and my story, my very mini, mini, mini story, is that I grew up in an alcoholic home. My dad was alcoholic. My mother was not. My mother was the codependent, who kind of kept everything together, and actually enabled my father to use, but he didn't ever realize that. And they raised seven kids, or I should say my mother raised seven kids. And my dad did get sober at the end of his life. So the fortunate thing for us is we got to know the difference between his alcoholism and who he really was.

But, you know, the important piece is that growing up, all seven of us were deeply affected by my dad's use. So there was a lot of domestic violence and neglect in my family. And that really had very much to do with the path that I went down. That, and my genetics. My grandfather, both my grandfathers were alcoholic. I had many aunts that were also alcoholic. So the genetic predisposing factors run deep in my veins, and I had all the environmental effects of being the child of an alcoholic.

And I went on to repeat the exact same thing in my own life. By the time I was 18 years old, I had two children, Danny and Karlie, pictured on the bench there. And at that point in time, I was a high school dropout. I dropped out in 10th grade. I was pretty much just living from place to place. So living in my parents' basement at times, moving all over the place. There's a lot of instability, and their father had spent a good deal of their life in prison. And, you know, I called that a bottom. But, you know, because I hear often that people won't go to treatment until they've hit bottom, but I happen to believe we need to tell them that

they've hit bottom, and that's one of the blessings I think that Healthy Start does is help women understand that they don't have to live this way anymore, and give them support and options for turning their life around.

Soon after my husband got out of jail, I had another baby girl named..we called her Erin. So in 1977, I had three children. I had drank throughout every one of those pregnancies, and I had been using a lot of other drugs besides alcohol. It was the Woodstock era. It was drug, sex, rock and roll, and I thought if I was just drinking wine on the weekends or wine when people came over or whatever, that all would be good. And, you know, and certainly, I had no idea. The literature hadn't even come out until 1973. I had already two children before that period of time.

So what happened was I ended up leaving their dad, and I married another man, jumped from a frying pan right into the fire. Married another man and went on to have two more kids. And, you know, I don't think there was a Healthy Start that was even in existence back then. Maybe there was, but I would have been a woman who would have benefited from what you guys do. But, unfortunately, I just didn't know what I did know. I married another man and went on to have two more children. And by then, I was on methadone to try to control my heroin addiction, and I drank throughout that experience. I never even thought of alcohol as a drug. It's just part of the fabric of my life, and I went on to have two more children.

My fourth baby died at birth, and my fifth child died at three months of age from sudden infant death syndrome. And, you know, it was...that was a long time ago. But, you know, maybe some of you have had that experience and maybe met women, and we never do forget that pain. But I will tell you that the only blessing behind any of that is that my daughter's death, when I found my daughter lifeless in her crib at almost three months of age, it was really the lightning rod that helped my father to get sober, and to help me, and I eventually got treatment, and to learn, you know, that I was alcoholic. I was a drug addict, but also an alcoholic.

And I had to really look at the cobwebs of my past. And I started going to GED classes, and I got my GED, and eventually got my master's degree. I will pull this together. Thank you for the comments that I received. Well, I never know what's gonna happen when I tell this story. That's [inaudible 00:23:50]. So forgive me for that. But, okay, you know, what I realized was that my daughter, who is shown here with cerebral

palsy at age 10, actually had fetal alcohol syndrome. And this is my sweet like Karlie. She has a non-existent top lip, a very flat area above her lips, which is called your philtrum. And if you look at her eyes, if you were to measure her eye opening with a ruler, her eyes splits are a little bit smaller than normal. So I realized in early recovery that my Karlie probably had fetal alcohol syndrome and not cerebral palsy.

So here's the deal. I took it down to Georgetown University Hospital and had Karlie diagnosed with fetal alcohol syndrome. Gave them the history, and, of course, my daughter has full-blown FAS. I had five children, you know. Today, this is how my life looks. Karlie is now 44. She just moved out of the house for the very first time last year. She's the love of my life. She's very sweet, but Karlie has intellectual disability. And she's victimized very easily, so she always needs to have someone with her and watching over her. You know, she's still, she's just an incredible person.

My other two kids don't have any diagnosis, but they could certainly have effects that we don't really truly understand. I believe both of my children that died, died as a direct consequence of being exposed to alcohol. And I can tell you the good news is that I'm not with my second husband, who was abusive. I am not with him. I have been happily married for 26 years. I have been sober and drug-free for 33 years. And I don't know if I mentioned, I actually have a master's degree and work in the field of FAS, which I have done for many years. So, you know, I had an opportunity to try to give back and make some good out of all the damage that my addiction had played out on so many people.

So I mentioned, you know, alcohol is a teratogen, and any amount of alcohol, whether it's beer, wine, or hard liquor, can damage the fetus in the same way, and if you look at that chart, they're all equal. So a beer is the same as a shot of booze, a can of beer. And one of the things we don't know, we know that if you give animals alcohol in a really healthy environment and just give them alcohol, they actually create birth defects in the lab. So one of the things is that we don't understand is why isn't every infant affected in the same way, and that's one of the questions that research continues to work on. So it seems that some children seem to have very severe effects with maybe one or two dosing and exposures, and others can be heavily dosed but not show some of the measurable effects. And again, I'm saying measurable because some of those effects are hard to measure for.

And, of course, one of the things we've got going on in today's world is

this whole prescription drug epidemic. You know, and again, I know it won't surprise you all to understand that we use, we consume 99% of the world's supply of hydrocodone. We are a prescription-writing culture, and it's not that way in Europe and a lot of other countries. And some of the stats are that 90% of women will use some form of prescription drug. And I'm not saying that every prescription drug, by the way, is dangerous. Some are absolutely necessarily. Over the last 30 years, the first trimester use of prescription medication has increased more than 60%.

And then we have a whole epidemic going on with, you know, opioid overdoses, with infants being born with neonatal withdrawal syndrome, NAS. And, again, I know I'm singing to the choir here. So we don't really know, by the way. We don't know because the research really hasn't been done on when women combine alcohol with a whole array of other drugs and things like poor nutrition, trauma, stress. We really don't know. But what we do know is all those things can damage the developing fetus. So that's the important message. None of this is good, but if you have to pick the worst [inaudible 00:29:15] titanic, it probably is the alcohol one.

We'd known about this really since ancient times. It was written in many different ancient documents, including the Old Testament, where an angel appears to Samson's mother, who is newly pregnant, and says to her, "Behold thou shalt conceive and bear a son. Now drink no wine or strong drink." Some believe that the Bible actually warns us not to drink if we want a healthy outcome. And we have physicians who were treating pregnant women with IV alcohol. They were giving them an IV to stop their contractions, and they were giving them enough alcohol for six to ten hours, where they would be legally intoxicated by today's standards.

So some of those physicians are still practicing, and that's where there is a lot of confusion around alcohol use during pregnancy I think with physicians. This is a great chart. This is the fetal development chart, and it helps you to see how a fetus develops, and it's that it's all about timing of the dosing. So if a woman drinks, what is especially troubling is the higher level dosing, the four drinks at one time. Don't get me wrong. Any amount can damage neurons, brain cells. But it's the higher level dosing, four drinks, four beers, four glasses of wine, or maybe even one Long Island. I see that may have as many as four shots of liquor in it.

If those are drank during the first trimester, it can affect whatever

happens to be developing in the fetus in that day. So it's the heart or the eyes, the limbs, the palate, whatever is developing, that they can be affected. Now, again, know that throughout pregnancy, brain cells can be damaged, and certainly the growth can be impacted, most significantly during the second and third trimester. Excuse me forcoughing.

The acting director, Dr. Ken Warren of NIAAA is on a video on our YouTube site, and he's talking about a very large international CIDS study, sudden infant death syndrome study, where they were looking at alcohol as a possible causal factor, and he is quoted as saying alcohol use while pregnant is a leading causal factor in those fetal and infant death, and that is including CIDS. So, again, there's a whole lot of things can happen that women may not even be considering. They may say, "Well, I don't know anybody with FAS. My mother drinks [inaudible 00:32:22] ten of us." And they may not fully appreciate that many of the symptoms can be hard to measure for, or we call them something else, like in my situation, cerebral palsy. And they may not think that CIDS or miscarriages or stillbirth can certainly be secondary to prenatal alcohol exposure.

So just a little bit about the face. I don't wanna focus much on the face, but I think the interesting piece here, this is the researcher, who is showing you a mask that was exposed to alcohol on the left, and she's comparing the features to a human. And you see the philtrum is flat. The eyes are underdeveloped. The head circumference is small. But the interesting piece and why I put it in there, this occurs in human days, really on the 17th day after pregnancy. So that is the window of time that a woman has to drink in order to have the facial features associated with fetal alcohol syndrome.

So that's why FAS or fetal alcohol syndrome is the most rare because in order to have FAS, you have to have the facial features. And just because a person has the facial features doesn't mean that you would necessarily pick them out in the crowd. So all of these children are Russian children, and they all have...are considered positive for facial features of fetal alcohol syndrome, which, again, includes the eye opening. They measure the eye opening. They're going to be just a little smaller than what would be considered in the normal range. And the real discriminating features are the thin upper lip coupled with a flattened philtrum.

And for a positive for the growth, remember it's face, growth, and brain.

But according to the CDC guidelines, if the confirmed prenatal or postnatal height or weight or both, at or below the 10th percentile documented at any one point in time. So they may have a low birth weight. They may not. They may have a normal or even a large birth weight. They may not show growth issues until adolescence, or sometimes even adulthood.

And I included this chart here, and I will tell you a little secret. This is actually the face sheet of my 35-year old daughter, who does not have a diagnosis of FASD. And look at all of the health problems that she has. So again, it may not just be about FASD or about infant death or miscarriages. It may also be about lifelong health issues and health outcomes. So it's thought that because people that have been exposed to alcohol in utero don't do well with stress. They can't self-regulate. They have a lot of anxiety and can't kind of regulate that down. And because of that, they're at high risk for developing diseases. And in our families, autoimmune disorders, like lupus, runs in my family, and fibroid issues and things like that. So if you can't deal well with stress, you're much more likely to see the onset earlier and become very severe.

And this is just a graphic of a healthy brain, and it's comparing that brain to a brain that has been extremely exposed to alcohol. As a matter of fact, that infant died. But sometimes the effects on the brain are visible, and sometimes they're visible to an MRI, but not always. And this is a MRI slide showing what a corpus callosum, on the 8th slide, should look like. And on the D slide, the real interesting piece here is that these are brain images of teenagers that some have the facial features and have an FAS diagnosis. Others don't have facial features, but they were exposed to alcohol. But all the kids had the same brain anomaly. So the corpus callosum was malshaped.

And they also have found that a pretty large percentage also had a genesis of the corpus callosum or pretty much a non-existing corpus callosum. So the real issue is, is that alcohol causes the brain to be built differently. And in our world, we assume we...everything is based on learning theory. Once you start school, even preschool, we assume that a student is able to learn a principle, kind of understanding what we're saying to remember these concepts, and to generalize. Once we tell you this in this classroom, well, you understand that in this classroom, it's the same rule.

So, basically, an alcohol...a brain that's been exposed to alcohol can have a whole array of problems. So things like they may have...they

may respond slowly. I've heard it said, is that they have a 60-second brain in a 10-second world. They can't link cause and effect. They're disorganized. They have trouble moving information from one situation to another, poor judgment, difficulty with time and money. They forget information. They can't read social cues. And, basically, they think and behave much younger than they should be.

This is not an exhaustive list, but a list of co-occurring issues that we may see when somebody is diagnosed with an FASD. So it's very common to be, like, for instance, ADHD, learning disabilities, bipolar disorder, depression, anxiety disorders. And this is a great timeline showing an actual person with FASD at age 18. And one of the things about this disorder that's a little unique is that they have really good expressive language. For a lot of people with a developmental or intellectual disability, you can tell very quickly that the person has a disability. So sometimes in two minutes, you know, "Oh, this person has disability. I should slow down and rephrase maybe what I'm saying."

Not so much with these guys. So, excuse me, and it's why they oftentimes have so many troubles because people have an idea that they are much higher functioning than they really are. Excuse me, I have to take a sip of water real quick. But you see at age 18 that they read pretty well, but in all the other areas of life, independence, math, and so on and so forth, they really struggle. And unfortunately, for a lot of these guys, their math skills, their maturity level, their ability for independence, never really goes past that 7, 8, 9, 10-year old level.

So, again, just to kind of summarize what some of the things we just talked about, if you're concerned about a client or one of your clients is concerned about a child, be thinking about this kind of five areas of concerns. So you're thinking about developmental issues. Maybe delayed milestones. Possibly some of the facial features or growth features. Certainly if there was a history of confirmed prenatal alcohol exposure or certainly other family members that have been confirmed, that would be something that you should definitely follow through on.

And by the way, many of your adult clients may also have an FASD and never have been diagnosed. So, again, most cases are never diagnosed. Everyone understands maybe they struggle in school or they have ADD or they have a hard time remembering to show up to their appointment or what-have-you, but they never get the diagnosis. Very few physicians. I mean, it's handfuls in some states, are trained on how to diagnose. Birth mothers in some states can face incarceration, and

certainly would never admit to anyone that she drinks for fear of losing her children or going to jail. And, of course, birth families can live with the painful stigma and work to cover that up, and they don't want the diagnosis of FASD.

And one of the things that I try to work with when I work with families is to help them to not [inaudible 00:42:40] FASD, that it's not the end of the world. And I've worked to change their perception from, you know, linear to circular. Somebody doesn't have his license at 16, or is not finishing school at 18, or is not going to go off to college at age 21. You know, it's not the end of the world, you know, and that exceptions is a process. You know, it's not an event. It may take you some time, but it's one day at a time, and we're gonna do this together, is kind of the overarching theme.

And another aspect to this is I truly believe that families living with addiction, families living with FASD are resilient. Certainly ones that adopt children, that take in foster kids. These are really strong families. But I happen to believe that families living with addiction, of people that come out of families, you know, women that, you know, ask for help, that find recovery, these are survivors. These are some of the strongest women you're ever going to meet. And that should be the message.

And so what we try to do is to help them to develop these resilient characteristics so that they can learn to kind of get through this aspect of their life and move forward and not look at it as all doom and gloom, and to get to the place where they can enjoy recovery together. And one of the things that we need to do, of course, is that we educate them about addiction, why people become addicted. We want them to discover hope. You know, eventually find some serenity, and to get outside of their own pain and start to help others, identify their feelings and understand that there is hope to work it out and to find support and resources.

And eventually, a family recover, will start to assume prior roles, such as the children aren't parenting the parents, and the parents are putting boundaries on their kids, and they're not personalizing the behaviors of FASD, which is something very common. He does this. He won't listen. He forgets, and he knows it really irritates me. And it's like, "No, no, he's forgetting because he does not remember things very well." You know, I'm getting a message that I have five minutes, but I have 15 minutes. So, Megan, I'm sorry to...you know, if I only have five minutes, for sure, let me know. I have 15 minutes.

Megan: That's okay, Kathy. I was just gonna say five minutes, and then we could potentially take a couple of questions. But there are no questions [crosstalk 00:44:07]. Why don't I just pose that to everybody if we have...if you do have questions, chat them in. Otherwise, we'll let Kathy continue with her wonderful presentation.

Kathy: Okay. Okay, good. I'm sorry about that, Megan. I am...

Megan: No worries. No, no worries.

Kathy: [crosstalk 00:46:01] comments and talk at the same time is like, boy, talk about...Okay, so...and we talked...I wanna talk, spend a little bit of time here talking about the stigma. You know, I'm all about helping to get the right diagnosis, but one of the problems is, is the stigmatizing thing to carry. And I will tell you, as I mentioned, I'm 33 years in recovery, and it's still isn't easy to tell a new neighbor that my child has FAS. They automatically assume I adopted her because I look like such a wonderful, pleasant person now, not like I looked like in my addiction.

And, you know, I have to turn around and tell them, "No, I actually drank when I was pregnant, you know." But I didn't know, I didn't know that, you know, it can be a very shaming thing, and I actually think we need to change the name of it. But the bottom line is, it's not only difficult for the birth mothers, it's difficult for the entire family. So my children, my other children, my daughter's cousins. My mother had a terrible time with this diagnosis, telling her friends that her granddaughter had FAS because, you know, you have to kind of, you know, explain it, and it's a very difficult diagnosis to live with, and it does require additional support.

Because of that, we started a program called the Circle of Hope. There is the information. If you have women who have used any substances during pregnancy, please refer them to the Circle of Hope. We provide mentors. We have a private Facebook. We have conference calls. And we try to support each other. Again, in terms of the stigma, we have put out a call to action to all of the government agencies that deal with FASD and advocates around the world, and it has really been so well-received. I actually presented this in London last year. All of our researchers through NIH and CDC are onboard with this.

We have changed the language. It used to be language like FASD occurs when a mother, when a pregnant woman drinks, or when a woman drinks alcohol during pregnancy. Now we really wanna get it off

the woman, off maternal, off mom, to it occurs when a fetus is exposed to alcohol. And we also are very big on promoting person first language. So we don't say FASD kids. We say an individual or a child with an FASD. And also, you know, we do a lot of work with physicians and nurses and social workers and Healthy Start workers on, you know, anyone that might work with especially high-risk mothers, to learn that their words do matter, to be gentle, non-judgmental. Listen to them. Stick to the facts, to understand that you may be the only person in her whole world that gives her five minutes and that really cares about her and her welfare and her child's welfare.

And again, it's important for all of us to understand the facts, that we're giving them the best possible information, and reminding her that, you know, you want the best for her and her family. If you go to our website, please check out our Stamp Out Stigma campaign. We have videos on our site there, on our YouTube site, and somebody asked about...oh, somebody asked about a video where a woman is drinking. Oh, I don't know about that one. Do you recommend showing the mother that you know is drinking the YouTube video?

Yes. Here we go. I'm sorry for that. I misread the question, but let me start over here. If you go to nofas.org, you'll find our Stamp Out Stigma campaign. You'll also find our YouTube site. We have videos there of birth mothers from across the world telling their stories about drinking during pregnancy, but how they got past that and through that. I would highly recommend showing those videos to women at the Healthy Start sites. We also did a movie with support [inaudible 00:51:11] a few years back. It's called "Recovering Hope." We have that available for free at NOFAS. If any of you would like it, it's also available I believe on our YouTube site.

But just to close out some of what I wanna remind you with the stigma, is it's folks like you guys that are really gonna make a difference because you get it. You get the women. You get what's really happening. Please help us take actions. As long as we allow women who suffer with addictions or have a child with an FASD or, you know, have given effects to a child with opioids and opioid withdrawal, you know, we need to be their voice. We need to take action. We need to speak up even if it's a co-worker that says something very stigmatizing and hurtful about one of our women, we need to be the ones to have our voice heard and to stand up and remind people that these aren't bad women. These are women that have, you know, a terrible disease or have experienced really painful things. And maybe they're doing the

best they can.

We don't wanna support any legislation that is going to lock women up. So work with us to fight anything that's going to just kind of hand-select women, usually from underserved communities, and send them off to jail. And, please, post our stuff on social media. Let people know about this. We really do need your voices. And, again, so the takeaway message is, support women. Help them to find treatment. Consider the possibility of FASD in your clients or your clients' children. Some other resources besides NOFAS are ACOG has a beautiful page on alcohol and women. And the AAP has a toolkit that is just great. And if you wanna learn about FASD, that is a really good resource.

And here is my contact information, but you're certainly welcome to contact me at any time. And the best way is through email. And let's see. I think we still have a few minutes for questions.

Megan: We do, Kathy. Thank you so much for that presentation. I apologize for the distraction there. We're trying to rush along. I'm gonna go back to your slides here where you put your takeaway messages. So, folks, chat in your questions into the chatbox if you have any right now for, Kathy. You're getting...I see some comments in here. Just excellent presentation, and folks complimenting you, Kathy, on sharing your story and your presentation. Here is one question, what about the father? Can their alcohol use cause FASDs?

Kathy: That is an excellent question, and I don't know why I didn't mention that. No. The disorder I talked about today, FASD, is really something that occurs after pregnancy. So it's not genetics. So it's not happening, you know, it's not paternal effect. However, with that said, they haven't researched anything with paternal effects. There's been very little research. What I really...I try to push for it all the time. We really don't know how a drinking father may affect their unborn. Now it would probably be in the form of genetics because that's pre-pregnancy. So, but what we're talking about with FASD occurs after pregnancy occurs. So it really is about an environmental toxin, drinking something that's actually very poisonous to the developing fetus, and it's really altering the way that the fetus is developing, causing, you know, lifelong damage to the brain.

Megan: Thank you so much.

Kathy: [crosstalk 00:55:36]

Megan: And I did just...oh, go ahead, Kathy. Sorry.

Kathy: Go ahead. No, no, go ahead.

Megan: I did this chat out. There was a toolkit that was shared, and I believe it's on the NOFAS website for FASD Awareness Month, a toolkit. So I chatted that link out to everybody to check out as yet another one of those resources that Kathy had shared, or it complements what Kathy has shared.

Kathy: Yes, yes. For FASD Month and, you know, if you guys could even quickly pull something together in your sites to acknowledge FASD Month, it would be a great time. Maybe you wanna show them a video. One great video out there, now this would be for people that already understand what FASD is. It's called the "Eight Magic Keys" video. That is to help parents learn strategies if they do have a child with FASD. But, again, just showing the YouTube videos on our website and maybe doing an activity would be really great.

Megan: I'll pull this wrap up and upcoming reminder slide up. But I did wanna ask you another great question I thought that would be good to pick your brain on. One person asked, "I hear all the time that doctors tell women it's okay to drink occasionally. Why do you think this is the case?"

Kathy: Well, you know, that is another great question. And I think one of the things is that physicians don't learn about this in medical school, and that's a real problem. I actually taught at Georgetown for 23 years at their medical school, but most schools do not teach it. And they're oftentimes learning as residents from doctors that are practicing. So there's this mindset that as long as you're drinking, you know, little bit, but you're not one of them, so it's fine for you to drink. And, you know, maybe they drink during their pregnancy, or maybe their wives drink during their pregnancy.
But, you know, it really is rooted in ignorance. And if you go to ACOG, the American College of OB-GYNs, they don't mess around. They're very clear to say, "Nope, that's absolutely wrong. There is no safe known amount of alcohol that should be ingested during pregnancy."

Megan: Great. So I found the link for that, the "Eight Magic Keys" DVD that you shared. And I'm gonna put that in the chatbox right now to everybody just so they can have it in a convenient place. I did wanna

just give you a few wrap ups and reminders before we end the webinar. There is two webinars following this in September, one on grief, loss, and compassion fatigue on September 26th. And then another for an overview of Healthy Start for a...sort of like an orientation almost for new Healthy Start project directors, called "The Essentials and Overview of the Healthy Start Project Director's Guide" on September 28th.

There are going to be another round of discussion groups through the A Step Initiative going on, and look out for those, and look out for sign out for those. It will be happening October through November of 2017. This webinar, as well as all the other webinars, transcripts and slides, will be posted...they're recorded and posted to the EPIC Center's website. That's here at healthystartepic.org. Though I did include a...also, they're the separate page for the A Step resources that highlights those three foundational FASD-focused events, and that link is here as well.

And then we also have an evidence-based practices inventory that might lead you to some additional resources and practices that you may find beneficial as you're looking for resources on this topic. I wanna give a huge, huge thank you. Oh, actually, quickly, Kathy, are those videos that you've highlighted available in Spanish? Somebody just asked.

Kathy: No. But you know what? You can go to the Anchorage school district. Just Google that, Eight Magic Keys in Spanish, if that's the one you were interested in. I don't believe they have that, the DVD in Spanish, but we do have Spanish material on our website. Also the CDC does, and NIH does as well. So if you need Spanish materials, you can email me if you're not fnding them on our website.

Megan: Well, thank you so much, Kathy, for both sharing your testimony and for delivering such an informative, helpful presentation. It is just such a treat that you have made time in your busy school to present on this webinar. So thank you so, so much for sharing. And to all...

Kathy: Thank you. It's my honor, and thank you.

Megan: And to everybody on the webinar, thanks for carving out time in your busy schedules to participate in this webinar. Dawn, did you have any closing remarks really quick?

Dawn: I just wanted to thank Kathy Mitchell. Thank you so much for your presentation today and all the valuable resources you shared with the grantees. Thank you.

Megan: Great. Well, I think that concludes our webinar for the day, folks. Thanks so much for your participation, and hope to see you again on another, one of our webinars.