

Webinar Series

Fetal Alcohol Spectrum Disorders

August 17, 2020

- Presenters: Elizabeth Kramer, Child Welfare Information Gateway
Barbara Clark, NACAC
- Man: Since--Elizabeth, since we have a large number of people that have registered for this...
- Elizabeth Kramer: Yes.
- Man: It can take a second for the attendees to fill up. How [audio garbled] you all send a message to chat saying when you can begin your introduction? How does that sound?
- Elizabeth Kramer: That--I always jump the gun a little bit, Barb.
- Barbara Clark: That would be perfect. Thank you.
- Man: You said it, not me, but hey, it's all good.
- Elizabeth Kramer: It's OK. You can call me out on it. It's fine.
- [Laughter]
- Man: All right, I'm muting myself and I'm going to begin the broadcast, and wait for my message.
- Elizabeth Kramer: OK. Thank you. Hello, and thank you for joining us. Today's webinar is hosted by Child Welfare Information Gateway, the information dissemination service with the Children's Bureau, Administration for Children and Families, U.S. Department of Health and Human Services. My name is Elizabeth Kramer and I'm the senior manager for knowledge transfer and information management at Child Welfare Information Gateway. This webinar is one of several that we are offering virtually to help ensure that critical information is shared with professionals and families during the COVID-19 pandemic, when we are prevented from gathering in person and challenged to continue to work with children and families in new and innovative ways. Today's presentation was originally scheduled as the breakout session for the National Foster Parents Association annual conference. Just a few notes. We are recording today's webinar, and we'll be making this recording available on our website at www.childwelfare.gov. All participant phone lines are

muted at this time, and we ask that you submit questions in the Q&A box. We will answer questions at the end of the presentation as time allows. At the end of the webinar, you also will receive a link to a short survey. We ask that you please provide us with your feedback on this webinar. And now I'm very excited today to introduce our session "Getting on"--excuse me--"Fetal Alcohol Spectrum Disorders." Our speaker today is Barbara Clark from the North American Council on Adoptable Children, or NACAC. So, Barb, now I'm going to turn it over to you.

Barbara Clark:

All right. Thanks very much. Really excited to be here with you guys. I sure wish I could have been there in person to see everybody in June, but this is life. So, again, as was said, my name is Barb and I just wanted to share with you guys that I am an adoptive parent. I have 4 children. They are 17, 18, 20, and 21, and Fetal Alcohol Spectrum Disorders is something I've been really passionate about for the last 15 years or so, since my oldest daughter was diagnosed with the Fetal Alcohol Spectrum Disorder. So, I am going to be sharing, you know, real-life experience and stories and that kind of stuff a little bit. But I'm going to say this right at the beginning: we're not--I'm not able to do kind of my full presentation that I often like to do or that I would have been doing in person. But at the end of this, I am going to be able to direct you to our NACAC website, where there is a webinar that goes a bit more in-depth, and we're going to be able to go today.

So, kind of the starting place, though, for Fetal Alcohol is having to understand exactly some of the kind of details behind it and how it plays out in some of our kids, and so, with that, I'm just going to jump into it. And we definitely will be able to take some questions at the end, so, hold your questions and then you can type them into the chat box and we'll be happy to answer them. So, one of the things I like to do, though, with Fetal Alcohol is I like to frame it within a trauma lens, and Dr. Bruce Perry, who is pretty much the international expert on childhood trauma and is amazing, I've been to some of his lectures, and he kind of puts category and--or trauma into 3 categories. So, he talks about intrauterine insult. So, this is a developing fetus who, in the womb, is experiencing trauma, and that could be exposure to drugs or alcohol, but that also could just be stress during a pregnancy, right? That could be a mom, a woman who is pregnant and is under high amounts of toxic stress for a consistent time, right? All of us have stress pretty much on the daily. But if we have ongoing high levels of stress, that's more referred to as toxic stress. And when we have that, when we have any kind of stress, cortisol is going through our body. So, if we have a high level of stress for long periods of time, that is going to be producing a lot of cortisol that is going into the womb and having--can have an impact on the developing fetus and on their brain and their other aspects of development.

So, intrauterine insult is the first type of trauma that our children in society can experience. Then we also look at there's early neglect. So, these are children who, in those first several years of life in particular, I mean, neglect can happen at any point, obviously, but in those first years, there is a ton of research showing how important nurturing and attentiveness from a parent or a caregiver is to the developing brain in particular in those first couple of years of life. The brain develops in the first 4 years of life at the most rapid rate that it ever does during our lifetime. So, it's really important that our children are getting the right kind of nurturing and love and attentiveness that they can in those years. Many of our children that are coming into the child welfare system or into adoptive, foster, or kinship families are not getting the nurturing that they need in those first years. Could be for a multitude of reasons, right? It could be a mom who has postpartum depression. Could be a mom who's in a domestically abusive relationship. Could be a child who was in an orphanage. Just tons of different reasons why that might be. It could be an intellectual disability or addiction that maybe--that the mom or the parents are struggling with. And so, that is a huge form of trauma to just not get the--one of--what the early childhood development people call it is serve and return. Like, even playing peek-a-boo, right? Playing peek-a-boo with an infant is serve and return, right? We--you know, they respond, we respond, and it goes back and forth like when we play tennis. Very, very important to a developing brain in that first year in particular of development. So, that's the second type of trauma that many of our children who are coming into the foster care and child welfare system can experience.

And then most of us, when we hear the word "trauma," we think more of the classic trauma of a child either witnessing or experiencing verbal, physical, or emotional or sexual abuse, right? All of those are our trauma and that's what--when we hear the word "trauma," that's what a lot of the times we think of, and absolutely that's a huge form of trauma with the capital T. Car accidents and medical trauma also can have an impact on the child's brain as well. So, unfortunately, what we are seeing in a lot of our foster families, though, and for the children that are in those families, is many of them have two if not all 3 types of trauma that are listed here. That's going to have a significant impact on their behaviors and on their lifetime abilities and struggles, for example, and so, what we're mostly going to be focusing on today here is Fetal Alcohol Spectrum Disorders, which I always like to say is one of the earliest forms of trauma that many of our children in foster care and adoptive families experience.

So, that's just a little bit of framing here for us. I also like to throw this in here, too. A child not being with their first family or their biological family in and of itself is also trauma. And so, there's huge trauma in being separated from biological family. And so, that also is trauma. So, I get asked this question all the time. I do training--well, pre-COVID--all

around the country. Now I do it all from my bedroom, which I'm getting really sick of, doing it from my bedroom, but I miss the interaction and seeing your faces big time, because I'm an extrovert, so, I'm kind of losing my mind here. But one of the common questions I get is "What's worse, drugs or alcohol?" Clearly, we don't want our children exposed to either in utero, but the Institute on Medicine, the IOM, has deemed that of all substances of abuse, including cocaine, marijuana, heroin, even meth, alcohol by far causes more serious neurobehavioral effects for a developing fetus. So, clearly, we don't want our kids exposed to either. But if it's just drugs, the impact is usually not as severe. But the big challenge that we usually have is there definitely are some women out there who are using illicit street drugs and not using alcohol, but the majority of women who, when they're pregnant, if they're using drugs, they also likely are using alcohol on top of that. But we don't--we can't--they don't really test for alcohol at birth. They can do tests for drugs if it's suspected, but the alcohol usually doesn't show up. And so, that's not tested for. So, a lot of times in foster care, we will know that a child was exposed to heroin or cocaine or meth or whatever it is, but we might not know about the alcohol. So, that's an interesting thing we're dealing with.

This chart here actually shows, you know, I took--we--I took this with and looked at some of the different research of various drugs and also alcohol. And you can see that the alcohol has a much stronger impact in those areas, the--what is it, 6 or 7 areas that are listed. Again, I'm not saying that drugs are not going to have an impact, because they are, but it's just not quite as severe most often if it's just that. So, little chart that you can look at. And again, these handouts will be available at some point here to you guys.

So. Fetal Alcohol Spectrum Disorders. Most of us have heard of Fetal Alcohol Syndrome, but in 1996, a little while ago, right, they actually made this a spectrum disorder, but not everybody's knowledge has kind of caught up with that. Whenever the medical community or mental health community makes changes, it takes a while for it to catch up in society.

So, FASDs are a set of physical, behavioral, and cognitive disorders that can affect people who were prenatally exposed to alcohol. It does--it does not affect everybody the same way, and we'll talk about that for a few minutes coming up here. What Fetal Alcohol Spectrum Disorders are is they're a permanent disability that result in a lifetime of brain injury or brain damage. And that's one of my biggest goals all the time when I'm working with foster families, is to help us to reframe how we're looking at our children because often kids with Fetal Alcohol look like willfully disobedient children who are making poor choices and are trying to make our lives, you know, challenging or something like that, but really what we're dealing with is a child with an invisible disability,

an invisible brain injury. And so, even with my 21-year-old daughter here, that's kind of the language I use with her when we're talking about stuff. I won't say, "Because of your FASD," I'll say, "Because of your brain injury." And so, just a way of helping us kind of reframe that.

What are the things that are under the Fetal Alcohol Spectrum? These are the main diagnoses that you might be a bit--you might see. One that we--most of us have heard of is Fetal Alcohol Syndrome. So, with that, there's 3 facial features that are common with that, and I'll show you those quick and then we'll click back to that slide. So, the 3 facial features that are common is a smooth philtrum, and the philtrum is that bump, that ridge, between your nose and your upper lip. So, a smooth philtrum is one of the facial features. A thin upper lip is the second one. And then short palpebral fissures. That means small eye openings. And so, those are the 3 facial features that are common with Fetal Alcohol Syndrome. There's others but these are the 3 they have to have to get that diagnosis. There's just, like, 3 to 5 days early on in pregnancy when those facial features are formed at something like days 17 to 21, but there have been women who have drank on those days and their children did not have the facial features. So, they still don't know exactly why it happens to some and not others.

So, again, so, FAS, those 3 facial features. They have to have growth deficits below the 10th percentile, but they can outgrow that, so, it might be as they're getting a little bit older, they might actually be the 15th or 20th or 50th or whatever percentile, but early on in the early years at some point, and it might not have been at birth, but below the 10th percentile. And then they also have to meet the cognitive neuropsych profile. So, they do neuropsych testing and they look at 10 different brain domains and they have to be struggling in at least 3 of them. So, that's FAS.

pFAS, Partial Fetal Alcohol Syndrome, does not mean partially is challenging. So, I always have to note this, that any of these 3 or 4 things that you see listed on this slide can have various levels in mildness or severity in how it impacts a child's life. The factors that are going to go into that are vast, and part of it also has to do with if they received other trauma in early years or that kind of stuff, but I've had kids with Fetal Alcohol Syndrome who are low-functioning with IQs below 70, when I'm working with families, and I've had families that have kids with Fetal Alcohol Syndrome that have IQs that are 120 and higher. So--but it is more common for Fetal Alcohol Syndrome to have a lower IQ, but not necessarily. So, and actually, IQ has been shown to be a protective factor. The lower the IQ is for our children, if it's below 70, they actually have better life outcomes if it--when we're looking at Fetal Alcohol, and the reason for that is they qualify for the right supports that they need and because their disability is more visible to us, we're more patient and understanding and getting them the right supports.

But--so, pFAS, Partial Fetal Alcohol syndrome. That one means they don't have all 3 of the facial features. So, maybe they just have one or two of the facial features, or maybe they have the 3 facial features and not the growth deficit. So, that's pFAS. But they still have to meet the cognitive profile when they do the neuropsych testing.

The ARND, though, the third one listed there, Alcohol Related Neurodevelopmental Disorder, that replaced--in 1996, that replaced Fetal Alcohol Effect. So, that might be a term that some of you guys have heard of or have seen kids diagnosed with. These children have none of the physical features, they don't have the face and they don't have the growth deficits, but they did receive the brain damage from the alcohol exposure. This is the truly invisible disability that is on the spectrum, right? These 3 ones on the top here above the blue bar are in the--these are medical diagnoses. So, these are in the medical diagnostic manual that doctors use, right? So, the ARND is an invisible one.

On the bottom here, though, in the DSM 5 that came out in 2013, in the back of the book, they also--they added something in there called ND-PAE--neurodevelopmental disorder associated with prenatal alcohol exposure. Now, we're not seeing that used all over in the country. I'm seeing it used more out on the East Coast more than I am anywhere else. So, it can be used, and that's something that a mental health practitioner can diagnose with. But these are kind of the things that are on the spectrum. Just for you to be aware of that when you're seeing different, you know, paperwork and stuff coming through for kids.

But an important thing to note is that only 10% to 20% of the children who are on the Fetal Alcohol spectrum actually have the facial features. And so, what I am seeing happen to families--foster, adoptive, and kinship families all over the country--really often still is, they might actually even bring this up to a pediatrician or a doctor or a nurse practitioner or a therapist or something and say, you know, "I wonder if this child, my child if they might have Fetal Alcohol," and professionals all the time are looking at the child and saying, "Nope, he or she doesn't have the face, so, that's not what we're dealing with." That is really, really old school, way over 20-year-old information that, for some reason, we've had a hard time getting our medical and mental health professionals to catch up on. So, the face is actually rare. The more common one to have is the Alcohol Related Neurodevelopmental Disorder. So, if you do have a professional ever who is giving--is telling you that and stuff, if there's a way, depending on your relationship with them, and if you find if there is ego issues or not, to try to get them the right information and to say that you've actually had some training where you've learned that that's actually not the case anymore through research. Otherwise, you just find a different professional, right? We've all had to do that enough. But that's not always possible, either. And I

do--I've done a lot of trainings, actually, at hospital systems and clinics and with doctors and literally will have pediatricians lining up afterwards, being blown away by not knowing this. And even--the unfortunate thing is we even have doctors who are graduating from med school today who are not getting the right information on this, and so, hopefully that's going to get caught up here soon.

Some of the factors that go into if a fetus receives the damage from the alcohol exposure--from the alcohol is--the first one is timing of exposure. So, we know that pregnancy is split up into 3 different trimesters, and by far the most damaging trimester to drink is the first trimester, but it is not safe to drink during any of the trimesters. And so, you know, many people in that first trimester, or at least half of it, even, don't even know that they're pregnant. And so, actually, the most likely person to have a child with an FASD looks like me, who you can't see me right now, but I had a picture up there, right? It's a white middle-class college-educated woman, is the most likely to have a child with this. But I would also be the least likely to have a child who was properly diagnosed. Most of the time with that kind of a family, we are seeing misdiagnoses and they're being diagnosed with something else. Often, it's maybe autism that's a common misdiagnosis. ADHD, Oppositional Defiant Disorder, Conduct Disorder as they're getting a little older. Reactive Attachment Disorder is also an extremely common misdiagnosis.

So, it's just important to know that—so, you know, we like to say that there is no safe amount of alcohol to drink during pregnancy because that's what the research really shows. There are still some professionals out there who will argue on that and say it is OK to drink lightly. I'm telling you it is absolutely not worth the risk. And one of the things that it is showing in the third trimester, for example, if a woman is drinking lightly, it can slow down the cognitive processing skills of the child, for example, so, just not worth the risk.

Resiliency of the fetus, though, is another one, and I'm going to flip to this slide here quick. In research that was just published last year in 2019, where they were looking at twins who were exposed in utero to alcohol, with the fraternal twins, they were seeing quite different outcomes for the child, but for identical twins, the brain injury was much--it was more similar. And so, these are children who were exposed, you know, with--to the same amount of alcohol on the same days of pregnancy, but if they didn't have the same kind of genetic makeup because they were fraternal twins, the damage was various--varied greatly. So, that's something that shows resiliency is one of the things, too.

Metabolism and diet of the mom is a huge one, though, as well. And so, you could actually have a woman sitting next to me right now who is

the same age as me and weighs the same as me, and we could each have a bottle of beer, a glass of wine, or a cocktail or whatever, and have different blood alcohol levels because people metabolize alcohol differently. And that's the case for the mother and the fetus and, as we know, smaller people metabolize alcohol at--usually at quicker rates.

And so, in that first trimester, the fetus doesn't even have a fully developed liver that can metabolize the alcohol very quickly. So, often, the fetus, their blood alcohol level as--is at a much higher rate than the mother's. But there's research also that's showing if the mother's iron level is low, that there is generally more damage to the fetus. And so, we know anemia is really kind of a common thing in our country, where women have low iron levels in their blood, and so, that's another thing, and if we are talking potentially about an individual, a birth mom, the biological mom who's maybe struggling with addiction and maybe living kind of a more at-risk kind of lifestyle, we know that it's--that nutrition often is something that people in that situation struggle with. So, if they're having poor nutrition on top of their alcohol use, that can mean higher impacts to the developing fetus.

And then the other thing I like to talk about, about the timing of exposure is I--so, again, I don't know if I said this, but I live in Minneapolis, Minnesota, and this is--I work a lot in Minnesota, and I used to work at an organization called Proof Alliance. Their former name was the Minnesota Organization on Fetal Alcohol Syndrome. And when I worked there, I worked with, you know, foster and adoptive families, but also with biological families, and there was one family that I worked with, the mother had been a college student at the University of Minnesota and she had been partying. This was 17 years ago now. She was partying, like many college students do, and all of a sudden had a 10-week unplanned pregnancy. So, she went to an OBGYN and she told him right away, "Oh, my gosh, I have been drinking a lot." And they said, "Well, stop," you know, and that is what we do recommend. If a woman ever has an unplanned pregnancy and has been using alcohol, the recommendation is to stop immediately and, you know, if possible. Again, if you're struggling with an addiction that--it's not that simple as just telling somebody to stop. But anyway, she did stop, and she was so concerned that she actually got a referral to a geneticist while she was pregnant and saw a geneticist. They did testing. They said, "Everything looks fine. You should be fine." Her son was born. He had high Apgar scores. He had a healthy birth weight. He developed typically in those first couple of years, you know, hit the milestones developmentally when he should, but as he was getting a little bit older every year, he was a really challenging behavioral child. And even by the time he was in elementary school, he was having--he ended up in a residential treatment center because he was fire-starting and doing just really tough things. All along, there are very--and this woman had gotten married, had two other children. This child had no other trauma except

for 10 weeks of exposure at the beginning of pregnancy. And she, all along with all the various supports and interventions and therapies they were trying, was saying that she had drunk the first 10 weeks, and all the various professionals kept saying, "Oh, he doesn't have Fetal Alcohol. He doesn't have that face." So, finally at about 8 or 9, they got to an FASD-competent person who was like, "Ooh, we should send you to an FASD diagnostic clinic and look into this." And sure enough, he was diagnosed with it. Now, the bummer on that is they missed 9 years or so of the appropriate interventions, and were banging their heads against the wall, and I'm not saying after they changed things up, they weren't also. But things could have changed a bit had everybody been aware of this earlier on, and we--and she and her husband could have done things a little bit differently, and, you know, some of the challenges, and he's now 17 and still really, really, really struggling, could have been different.

So, it's just important to note that, you know, this is something that impacts our society all the time, not just foster care, although it has high rates of this in foster care. The other factor that can have an impact is the blood alcohol concentration of the mom. So, even people who say it's OK to drink during pregnancy lightly will admit that high levels are not safe.

Prevalence. So, in 2018, some research came out showing that about one out of 20 children have an FASD, but most of them go undiagnosed or are misdiagnosed. So, what the researchers did was they went to 4 different communities around the United States. They went to a middle-sized Midwestern town. They went to a small mountain town, an inner-city diverse area, and then a suburban area, and all 4 of those communities, one out of 20 is what they found in research. They studied, like, 70% of the first graders, I believe, and one out of 20 of them should have had this diagnosis, but weren't. So, it's twice as common as autism, which is between one out of 40 to 59, depending on which researcher stuff you're citing. So, it is, and this is not within just the foster care system, where it's actually much higher than it is in the general population. So, this is what most of us in the FASD world believe. This is the number-one public health epidemic. It's leading to all these secondary issues of homelessness, of teenage pregnancy, addiction, all of these things, because of the way that the brain impairment kind of plays out.

A tough fact is that children with an FASD are 3 times more likely to be abused or neglected than a typically developing child. So, if you're out there currently parenting a child with Fetal Alcohol or have in the past, or one that you're suspecting, even, you know how challenging they can be. They're awesome, amazing kids. My daughter who's 21 is so cool, but she is really hard. And so, because of that, they are more likely to be abused in certain families, and that's really unfortunate. So, that's why

they're at an even higher rate to come into the foster care system.

So, some of the red flags. Again, having a child just being in foster care is a red flag. Here in Minnesota where I live, I honestly believe we are the most FASD-savvy, competent state that there is, and it's because of Proof Alliance, this organization that we have that's been around for over 20 years that has done some phenomenal advocacy. They actually, about 3 years ago, were able to pass a law with our legislature that all foster parents had to receive annual training on Fetal Alcohol Spectrum Disorders, but this just last month, a month ago, they were successful in passing a statute that all children that come into foster care have to be prenatally screened for Fetal Alcohol. And they're providing the training to all the counties and agencies to do that. So, that's phenomenal, because NOFAS, the National Organization on Fetal Alcohol Syndrome, estimates that 70% to 80% of children who are coming into foster care were prenatally exposed to alcohol. So, it's also really common in a lot of international adoptions as well. We're seeing it in a lot of Russian, Ukraine, Kazakhstan, a lot of those countries. Korea, though, we're seeing really high rates of it. Korea has the highest rate of alcohol consumption per capita in the world. So, this is--it's hitting a lot of foster and adoptive families. If there's a history of chemical dependency for the biological family or for the child as they're in adolescence, that's a red flag.

We have a child who had some of those classic ADHD symptoms--the distracted, hyperattentive, impulsive, inattentive. They're doing--when they're looking at research, trying to look at the difference between ADHD and FASD, two of the things one of the researchers told me they've--that they've seen is our kids with fetal alcohol are more consistent rule breakers and they're more likely to be verbally and/or physically explosive. That does not mean a child with just ADHD doesn't struggle with those, but it hits our population with Fetal Alcohol at a much higher rate.

But I also tell the families I work with and when I'm doing trainings, I always talk about if we have two kids, one with ADHD, one with FASD, and let's say we do stuff to help them focus and pay attention. Maybe it's medications. Maybe it's we just sat and did a sensory activity before we sat down at the table or the desk to learn something for 10 minutes, and they both actually sit there and are able to focus and pay attention on some, you know, to this--to the topic we're working on for 10 minutes. And then maybe 30 or 60 minutes or 6 days later, if we ask them a follow-up question on what they sat there for 10 minutes and learned, it's much more likely that a child with just straight ADHD is able to retain and use that information and, you know, regurgitate it back out to us, where a child with an FASD, they might look at us blankly, like they don't even know what we're talking about. So, they have a harder time retaining the information, and a lot of times, they've actually

retained it but they can't find it and get to it in their brain because of the way their brain injury is. It's really complex and, again, in some of our more in-depth trainings you can find on our website, you can learn more about that. It has to do with corpus callosum damage to their brain.

OK, but these two bottom things on here for red flags are huge. If we have a child who has been in a foster family for a pretty good amount of time and has had consistent safe relationships for quite a while, and they're still continuing to make some of the same mistakes and to not learn from the consequences that you guys are giving them, that's a neuro disconnect. It is not neurotypical to not learn from mistakes and to keep making the same conse--or to keep making the same, doing the same choice over and over and not to learn from a consequence. There is something neurologically more than likely going on. In particular, again, at the beginning when they're first coming into a foster family and we're trying to work on safety and regulation and stuff like that, things can be kind of messy, but if it's--if they've been there for long enough, I would look into this if that's a consistent thing with a child you're working with.

Another red flag is multiple diagnoses. My daughter as--at 21 has over 23 things on--in her electronic medical record. Several of them are co-occurring or just misdiagnosed mental health things, but a lot of medical things, too. It's very common for our kids to have chronic pain issues, migraine, autoimmune, rheumatoid, vision, hearing, heart. There's 428 co-occurring common medical diagnoses with Fetal Alcohol. So, that's--but a lot of times, it's mental health stuff. If we have a child who is displaying some of those extreme behaviors of aggression, whether it's verbal and/or physical, and emotional instability, that's a red flag.

Sleeping and eating issues. Again, that family I spoke of who--the only trauma this child ever experienced was the first 10 weeks in utero, he has hoarding issues and sleeping issues, just like many of our kids who experience trauma outside of the womb. So, sometimes that could be from the neglect and abuse that they received out of utero, but it could just be also from their in utero trauma as well.

Another red flag--if they have an average IQ or a high IQ, but they're functioning at a much lower capacity than you would expect for what their IQ is, that's a huge red flag for Fetal Alcohol, and I go to IEP meetings here in Minnesota quite often with families and I'll have the school psychologist say something like, "Well, this, you know, he or she must have been really off the day we were doing testing because his IQ is 94 but his working memory was 68," or, you know, it's all over the map, and I'm just like, no, that's classic Fetal Alcohol. They have these huge strengths and huge weaknesses and just are really inconsistent.

Vivid fantasies and perseveration problems can be present. So, perseveration means to be stuck on talking about the same thing or obsessing about the same thing all the time. Maybe it's an activity or a person or an object or a toy. That's to perseverate. That's common. But our kids with this are the ones that are often telling these really whopper stories that don't make any sense, and it comes off to us like they're lying because they often do that when they're in trouble or when they're feeling anxious, but it's actually not because you've probably seen these kids actually start to believe it. It's a term called confabulation, and again, in some of the other webinars you can access, you can learn a bit more about confabulation and how to deal with it. If we have a child who can repeat a rule but can't follow it and then they don't understand why they're in trouble when they break it, even though they just told you what the rule was, that's a neuro disconnect again. That's not neurotypical. And then, of course, they're the one when their sibling breaks the same rule, they think the world should come crashing down on their sibling or on their friend or their schoolmate, even though when they break it, they don't understand why they're in trouble. That's a neuro disconnect as well and Fetal Alcohol--a red flag for Fetal Alcohol.

One thing I always like to point out is that a lot of our kids with fetal alcohol can do OK in those early years of life and not have really huge behaviors or huge struggles at school, even, or, you know, sometimes a lot of our kids struggle more in one place than the other. Maybe they struggle more in school and not at home or vice versa. It's more common that they do OK in school and their behaviors are more off the charts at home. But a lot of our kids do OK and aren't struggling at really high rates in preschool and early elementary, and there's a couple of reasons for that. They have very, very concrete brains, and so, they don't understand abstract concepts all that well, and so, early elementary and preschool, the curriculum is very concrete. It's your ABCs, your 1-2-3s. We don't give a lot of tests, except for spelling, which is kind of concrete, and some of our kids can do OK with that, but when you're in fourth grade and each grade after and then in middle school, the curriculum is becoming bigger and we're trying to get kids to use the higher-level thinking parts of their prefrontal cortex, and that development lags greatly for our kids with Fetal Alcohol. So, a lot of them were doing OK academically in those early years, and now all of a sudden, they're sitting in the classrooms and they're not comprehending what's being talked about. And for some of them, this is a new phenomenon. Again, some of them were possibly struggling before that. But—so, they're starting to have extreme anxiety in school and they're starting to feel dumb. And so, this is when we can start--that's the language that they would use, right? That they feel dumb or stupid or whatever.

And so--and so, what happens when you're feeling like that, when

you're sitting there in fourth, fifth, sixth grade and you don't comprehend stuff, is you're going to start acting out. You're going to start blurting out more in the classroom. You're going to start eloping from the classroom and refusing to stay in there, and who would want to stay in there? You guys have been to trainings that are--you don't understand or that are boring. I don't like staying in there. I want to leave, right? Hopefully you're not feeling like that today. But, you know, I wouldn't want to stay in there, either. And so, a lot of them would rather look bad than dumb. So, behaviors start to increase. Either that or some of our kids will start to more withdraw and be more quiet and more inward.

And so, the other thing that's happening, though, is most--a lot of our kids function at about half of their age. Actually, the vast majority of kids with Fetal Alcohol, if you take their age, if you have a 10-year-old, you're probably dealing with more like a 5-year-old. If you have a 16-year-old, you're probably doing more with an 8-year-old, for example. So, in those early years, in preschool and early elementary, it's parents and caregivers who set up birthday party invitation lists. You know, sleepovers, play dates, but then by fourth, fifth, sixth grade, we're letting the kids more self-select their peer group, and because of our kids' developmental differences, a lot of their classmates or neighborhood friends kind of start to pull away and don't enjoy hanging out with them. So, they're starting to feel more socially isolated. It's also when bullying ramps up in our school system, is fourth through sixth grade and middle school.

And so, here we have this child who's--many of them are starting to struggle academically and feel dumb and have more anxiety and behaviors around that. They're starting to feel more socially isolated, potentially bullied. Sometimes, they can have bullying behavior, but mostly, they're usually bullied. And then their bodies are starting those fun pre-hormonal changes of puberty. So, it's kind of this perfect windstorm of a whole bunch of stuff.

So, what we as foster parents and adoptive parents need to do when we start to see any of those initial signs, we have got to become the uber advocate to wrap around this child and to try to help the school system understand that, because I know I hear from many of our families that that's a consistent struggle, is the school looks at the child and their IQ and their strong verbal expressive skills, because most kids with Fetal Alcohol have huge verbal expressive skills. That's a strength. So, they appear more typical than they actually are generally. And so--but we need to get the school to understand this because if we don't, what starts to happen is all of a sudden we're having self-esteem issues and they're starting to struggle more with depression and self-harm and school refusal, eventually, which many of you have probably had to deal with school refusal. That's a nightmare when you have a kid that

doesn't care about a consequence or doesn't learn from a consequence.

And so, trying to work with their school system and understand that, their therapist, their--you know, whoever all is on their team to help them to know that. I'm happy to do training for schools. Obviously, I do a ton of that in Minnesota right now. Since all training seems to be virtual, it's really easy to do, too. But anyways, that's just something to be really aware of.

And then I do like to just point out, too, many of our kids who were prenatally exposed, they might have that failure to thrive and not be on track developmentally in those early years, in particular if there was neglect and trauma in the early years outside of the womb. But the majority of our kids with an FASD were actually developmentally on target in those first several years. And so, that's just an important thing to know as well. Early intervention is crucial. So, if you are currently or will be in the future fostering a child who is in particular under the age of 5 or 6, there are some huge interventions that you can be doing and would need to talk with their team about, right? With the case manager and social worker, whatever. But the medical provider--there is research that's just been published, 10 years of this longitude research, where they looked at choline, which is something that's in, I don't know, a bunch of different beans and liver and certain meats. It's also in eggs. It's in a lot of foods that have protein in them. But they did research where they gave children who were exposed prenatally these choline supplements at ages--between ages two to 5 years of age, and what they found was that the two- to 3-year-olds had the most repair for their neurocognitive functioning from that choline. So, the earlier the better. It wasn't as effective in the 4- and the 5-year-olds, although it was still helpful, but not as much as it was in the two- and 3-year-olds.

And I spoke with Dr. Jeff Wozniak. That research was actually done here in Minnesota at the University of Minnesota, and--about it, and what he was saying, like I said, "What do we tell foster families who have babies that, you know, that they--that we suspect or know for sure were exposed?" And what he said is as soon as they're on, you know, solid foods and allergens have been eliminated, that he would recommend a choline-rich diet, and eggs, for example, have that, but if you just Google the word "choline," you'll see what, you know, what foods it's in.

The other thing is, is you would probably need to print this research or email it or whatever you can do to your pediatrician or medical provider. They're not going to be aware of it because they can't be aware of every single disorder and all the research that goes with every one, but if you were to print it out and give it to them and say, "Hey, can you look this over and get back to me in two weeks on what your recommendation would be," for example, that would be a really good

idea, too. But the other thing, too, why early intervention is important is if we suspect this or if it has been diagnosed early on, we need to change our approaches as their foster parent, as their adoptive parent, as their parent because that is going to be, actually, the most effective intervention that we do.

Diagnosis. So, they look at--when you--they're--on this link that I put on the bottom here--NOFAS. They actually have, or you can click on your state to find what diagnostic clinics or supports there are in your state. Not all states have them, but most do. So, it can be a tough diagnosis to get. The things that they look at are the growth deficits. They look at the central nervous system problems that--the CNS is the brain. They do take a history of alcohol exposure, which sometimes we don't have, and that can really snag the diagnosis of this. If they have the facial features and meet the neuropsych profile, they will give the diagnosis out without confirmation. But otherwise, you have to have that confirmation in their case file or get it. You can't just say verbally that the birth mom or the birth family told you. They need to have it in some kind of documented form in general.

So, that's a little bit of the diagnosis. I get asked all the time, "Why diagnose? I have the list on here." The biggest reason is because it can decrease our anger and frustration with a child when we start to realize that they're dealing with a neurological brain injury and that it's not just willful disobedience, and that we actually have to change a whole bunch of our approaches and strategies with these children, is what we need to do. So--but I'm not going to go through this whole list, but it'll be on there so you can read it at some point.

If you--and I know a lot of times, many foster families and resource families actually have connections and relationships with the biological family or maybe seeing them on visitations, or maybe you could have your, you know, caseworker work on this. If there's a way that we could try to ask this--ask about exposure, even if it's been asked 47 times before, if you phrase it like this, because if you just say to a woman, "Did you use alcohol when you were pregnant?", most people are just going to say no because that's a loaded question with a lot of shame and blame and guilt and stuff in it. But if we ask it--if we just change it around a little bit and ask it like this, where we say, "Hey, is there any way before you knew you were pregnant that you could have been using alcohol?" And if you just say something like, you know, "Because that's happened to a lot of my family and friends. It happens to people of all races and economic backgrounds and lifestyles all the time," we actually see women being much more likely to admit if we ask it that way and take the shame and blame off of it. It doesn't mean they're not going to still have issues of guilt or feeling horrible about it, right? But you'd be much more likely to get the right information. So, that's just something you could also, you know, if you have a relationship and can

ask, or if there's a way that the caseworker can. I like to share that. I do have two slides on their strengths, and it's not because they don't have a lot of strengths. So many of our kids and adults with Fetal Alcohol are really charismatic, engaging, fun people to be around when their behaviors aren't driving us nuts. And unfortunately, their behaviors can be really, really challenging. But if you think about these kids when they're, like, on, you know, online and doing what we need them to be doing, they can be—they are so much fun, but unfortunately, their brain damage just can get in the way so much. So, again, this—you know, not every child with an FASD has all of these, but these are some of the common ones. But one of the things I like to point out on here is that many of them, the vast majority of them are really good with younger children, and that's a strength we should utilize, but we need to be cautious. I have had way too many foster families who have gotten into really sticky, really challenging situations where our kids with an FASD had done something inappropriate with some of the other siblings or foster siblings. And so, not many of them are probably good choices for baby-sitting. There's definitely some outliers out there who would be trustworthy in that, but because of the impulse control that most of them struggle with, it's not worth the risk, and they need high levels of supervision, which is exhausting, right? It's absolutely exhausting. And so, you know, I just—I like to point that out because I don't like our families to get into those really tough situations. So, I kind of have what—as I said at the beginning, I don't have enough time today to get super—go in depth and get into all the symptoms. I'll tell you guys a couple of the common symptoms. Impulse control is numero uno. It's the most common thing that most of our kids struggle with, so, that's why some of them struggle with verbal explosiveness, some of them with physical explosiveness. Some of them struggle with stealing. Rage—the raging behavior. Sexual impulsivity is a common one. They struggle with money management. There's this huge list of them. But again, what I wanted to just show you guys here is on our NACAC website, we have a webinar also that you guys are able to access there that's listed. But we also, me in particular, I'm—at NACAC, I'm the one that usually does FASD training. We're able to customize training for agencies or counties or territories or states or organizations, or even for parent groups that can be, you know, geared for child—because, you guys, foster parents, y'all know this. Your workers need to know this information, right? Your workers need to know more about Fetal Alcohol, and I've been doing a lot of trainings, you know, around the states, at some of the state conferences that are for the child welfare professionals. But we all need to know more about this so that we can help our kids to be more successful, and that's really what our goals are, right? We want our kids to do better and to be content and to be happy and successful and we want our families to not be so stressed out. And again, these are amazing kids who can cause a lot of stress. So, there's—I just wanted to share that with you guys, that link as well. And if you just go to our NACAC website and go to “Get training,” you'll be able to find

that if you weren't able to kind of get that--take a picture with your phone right now, right? That--but you'll be getting these handouts, too. They will be available somewhere that we'll tell you about. But you have my email. You can also email me questions at any point. There's my email right there for you. And with that, I am happy to take the questions that have been popping in. Look like--

Elizabeth Kramer:

Thank you, Barb. We have indeed gotten quite a few questions and you did answer a big one, which was that there was quite a call for your handout. So, Barb, if you will send them to me after this is over. I will send them out to all the registrants so you all have this information. Before I launch into questions, thank you so much. You packed a lot of really excellent information into a very short time. So, thank you so much for pulling this all together. Um, time for a couple of questions. First, could you speak just a little bit about breastfeeding and the effects on the child in terms of Fetal Alcohol Spectrum Disorders?

Barbara Clark:

Absolutely. Yeah. So, years ago, they used to say if you were using alcohol while you were breastfeeding, that you should pump and dump, but now they've realized that is not good because the alcohol is still within your system and just goes into the milk that your breasts are still producing. So, what--I believe it's something like 7 hours or something like that is how long you're supposed to wait after consuming alcohol when you're breastfeeding before you would breastfeed the baby again, so, it can have an impact. Again, it's kind of similar to that third trimester. It can slow down the cognitive processing skills of the child and have a couple of different neuro effects like that. So, it's definitely not recommended to have--be using alcohol while breastfeeding, or if you are, that you need to wait until that milk has left your body.

Elizabeth Kramer:

Excellent. Thank you. So, you had mentioned earlier that there is still a fair amount of folks in the medical professions that are sort of not really up to speed and if they don't see sort of the facial features there, they're not thinking Fetal Alcohol Spectrum Disorders. And so, the question is why is it, do you think, that this has been kind of slow in getting through to medical folks and what can we do to get this information out so there isn't so much misdiagnosis, both medical and, I think, mental health professionals as well?

Barbara Clark:

Right. So, you know, I should try to see if there's some committees at NOFAS, the National Organization on Fetal Alcohol Syndrome, that I could try to get on. I keep saying I think their number-one platform that they should be doing right now, or one of the number-one platforms, is they should be trained to work with the curriculum writers for medical school, for, you know, social work school, for teachers. All of the curriculum and books that our college and university systems are using need the accurate info in them, and it's not in there enough, and I think there needs to be a huge plug at that level. So, I don't know--I think, you

know, there's multiple things. I think there's--you know, alcohol is a sacred cow in our country, you know, and I don't even--I'm not a teetotaler. I don't believe alcohol should be illegal. But there's something where we get very, very protective, and you guys probably all saw, that during the beginning of COVID in particular, there were so many memes and posts out there about people using alcohol. We're all quite concerned, actually, that rates of Fetal Alcohol are going to go up because while people have been stuck at home, alcohol use has increased greatly. And so, you know, I'm not completely sure exactly why it hasn't caught up. It's one of those things that there still is not--like, if you look at how much research there is on autism as opposed to Fetal Alcohol, it doesn't even come close to comparing. There's so much more on autism. And part of the reason for that is there's...we know what causes Fetal Alcohol and we like to point the finger at the woman, at the mother, and we like to blame her for it. And, you know, I also believe prevention efforts are so important and we need to be doing that, but no amount of prevention effort is going to ever completely eliminate this because of the unplanned pregnancy things that are out there. The CDC came out, I think it was about 3 years ago, maybe more, with recommendations, just a general recommendation to the public saying if you are of childbearing years and you're sexually active and you also use alcohol, that you need to be on birth control, and many people got very upset about that, very upset about that, because they were like, you know, who's the government to tell us what to do with our body and they were like, first of all, it was a recommendation, you know, and second of all, it was because they're seeing these huge high rates of this, and the impact it is having on, you know, on so many aspects in our society now.

Elizabeth Kramer:

Mm-hmm. So, you raised a really interesting point about moms, but we've had a couple questions. What about alcohol use by fathers? Is there any connection with that and Fetal Alcohol Spectrum?

Barbara Clark:

What's so interesting about that, honestly, is 3 three years ago, and before that, when asked that question, when the FASD doctors, you know, the ones that do the research, everybody, the answer to that used to be that the dad's alcohol use does not have an impact, and then about 3 years ago, there was some research, some research that came out showing, oh, wait, it is having a little bit of--there is an impact. And so, it's still kind of an inconclusive thing, but it's not going to--what they do say is it's not going to cause the level of brain injury that it can if the mom is drinking while pregnant, but, you know, we do know that genetics are passed down and we do know that there's a genetic predisposition to alcoholism as well. And, you know, there's all of those kind of factors. So, that actually--there's still not a lot of clear information on that at this point.

Elizabeth Kramer:

OK. All right. And before I forget, when you said study, that made--

reminded me. Several folks had also asked if you had a link to the choline study. If you can send that to me with the slides, we'll send that out to the...

Barbara Clark:

I can do that. I can add that in there.

Elizabeth Kramer:

Fantastic. You had mentioned earlier that there is a lot of misdiagnosis of FASD and that one of the more common misdiagnoses is autism. So, could you speak a little bit to the similarities between autism and FASD?

Barbara Clark:

Well, the similarities are, you know, can be really--one is the perseveration and being stubborn and getting stuck on something. Another big similarity is sensory processing or sensory integration disorders. I've literally never seen a kid with Fetal Alcohol that doesn't have--struggle with sensory stuff, and the same kind of goes for autism. So, those are a couple of the similarities that are there for sure. You know, with autism, one of the really common things are some of those communication quirks things that a lot of kids with autism struggle with, and whereas kids with Fetal Alcohol generally can be really social and have good, you know, I mean, they don't have great social skills, but they could--they would easily be able to sit there with an adult, in particular. What their social skills lag on is having good skills to hang out with peers. But, like, my daughter was the one, for example, who was in, like, her school for many years, the district offices were in the same building and she would go in there every single day to chat with the secretaries in there because she's so incredibly social and she just--she can sit and talk with adults who have patience with her until the cows come home, but most kids with autism, and again, with both disorders, there's always outliers that don't fit it perfectly, but most kids with autism aren't going to be going into chat with the secretaries or do things like that, you know, because they struggle so much with communication. Um, and so, those--another very similar thing is being really concrete in how you see the world. Most kids with autism are very concrete, as are kids with Fetal Alcohol. So, there are a lot of overlapping, you know, kind of characteristics there that we can see.

Elizabeth Kramer:

OK. Let me see. We also had some questions about interventions that work, and specifically the two that are asked about are ABA therapy, or applied behavioral analysis, and also massage. Do either--have either of those shown promise?

Barbara Clark:

You know, so, for some of our kids, absolutely, and there's, you know, especially massage. You know, one of the things--I love Dr. Bruce Perry's neurosequential model and it's a, I don't know if you guys have read much about it, but there's great YouTube videos that he has. They're really easy to watch and stuff where you can learn more. And he always talks about how what we're doing often with kids with any kind of trauma is we're doing a lot of talk therapy or a lot of these different

therapies, DBT, whatever it is, who are looking up, who--which are things that are more focused on the prefrontal cortex, where you have to have high reasoning abilities and be able to problem-solve and do--have all of these skills to be able to do, and those are generally weaknesses for our kids. So, a lot of those therapies can be ineffective. Now, for some kids, though, they work, so, you might--you're going to know your kid better than anybody and whether something like that would probably connect or not with them. And so--but what he always is talking about is we need to start with therapies that work down more in the brainstem, down at the amygdala, where the, you know, fight/flight/fright part of their brain is, because that's where--when their brain is developing and they're being exposed to alcohol, for example, in utero, that's what it hits first. And so, most interventions are more effective that are down there in the brainstem. And those kind of things are like EMDR, for example, and I always forget eye motion.

Elizabeth Kramer:

Eye movement, desensitization...MDR. I apologize. I don't know the R off the top of my head.

Barbara Clark:

That one never sticks in my head. But EMDR, look it up, that can be one that can be really effective. A lot of the--again, occupational therapy with a sensory focus, from my experience, and other FASD experts I've talked to will say that OT with the sensory focused is generally the most effective intervention that we see with our kids. And so, other stuff is some of like the music therapy, equine therapy, pet therapy, you know, all that kind of stuff because that is more things that are based down in the brainstem. And as our kids are getting older and if, you know, if--making progress, they sometimes can move up to some of those higher-level kind of therapy interventions, but then we also have to remember that sometimes there might be some transition or something that happens in their life, and all of a sudden we need to back up and go back down to the brainstem. And so, you know, that's an important thing to remember with kids who have a trauma history, you know, and it could have just been maybe they learned, you know, something about their biological sibling, or maybe biological parent had a visit, or maybe biological parent passed away, or maybe they're transitioning from middle school to high school and that's got them in hyper-overdrive or whatever it is. There are times when we have to watch, and if we see them kind of going off the rails, that might be like, you know what? Let's take a step back and let's go back to these other therapies that were more effective, and ideally, and this is what Dr. Perry's neurosequential model tries to talk about is that in all 3 areas of our kids' life whether it's family and then it's school and then community kind of is where we've got, like, the therapies, the medical stuff. All that stuff is the community. All--ideally, we want all 3 of those places to be doing the same stuff and working from the same place. And so, again, I love schools, I love teachers, but not all schools understand this and there

has been an effort, you know, nationwide in the last several years for schools to become more trauma-informed. And so, trying to help the school to understand that, too, that OK, little, you know, Johnny's off the rails right now. Let's back off of, you know, math or whatever it is and let's have him have some more time in the sensory room or whatever it is.

Elizabeth Kramer:

Mm-hmm. OK. So, we have so many more questions and I know we're short on time. So, for our audience, what we're going to do is we're going to summarize some of these questions. Barb has agreed to put together some answers and we will send those out with the survey link and also a couple of additional resources, including the link to the choline study. Also, thank you to the couple people who told us it's Eye Movement Desensitization Reprocessing. So, EMDR. Thank you for that. I will try to remember that. I am going to close with one question for you. Could you talk to us a little bit about sort of prognosis? Are children with these disorders and, of course, every child is different in different, you know, has different, you know, strengths, but what is sort of the prognosis? Are we finding that these children are able to grow into, you know, happy, healthy adults and, perhaps, you know, be successful as parents themselves?

Barbara Clark:

Yeah. Absolutely. There's a lot of hope with this. So, here's the tough thing, and most foster families don't want to hear this. It usually gets harder before it gets easier, and the adolescent years which are hard to parent neurotypical kids...

Elizabeth Kramer:

Yes.

Barbara Clark:

really hard to parent these kind of kids with this type of a brain and to keep them safe in today's society in particular with social media, internet, and all the other kind of things that come along with society. So, what we say the most important thing is, if we can keep them safe and keep a strong relationship with them, they are more likely to have better outcomes. Because what we see in those young adult years in the 18 to 30 years of age, that is actually the hardest time for them. So, a lot of parents are like, "Are you kidding me? I didn't think it was going to get harder than these teenage years are." I'm like, "Yeah. Sorry." For most of them. It is actually harder because they've got newfound freedom and they're--even if we, you know, even if they're under guardianship, it's still really hard. And so--but if we can maintain a strong relationship with them and a strong support system around them and try to keep them out of addiction, that's a challenge, and what we see with a lot of them is as they're getting to about 30 years of age or so, we're starting to see many of them start to do better. And actually, there's a podcast--Jeff Nobles, an FASD trainer like me up in Canada. He's a great guy. He's got a podcast called "The FASD Success Show," and there is--it--there's 30-some episodes and at least 3 of them

were adults that were in their 40s or above with Fetal Alcohol, and they were my favorite ones to listen to, and every one of the 3 people. I listened to said right around 30, things changed for them and they started doing better.

Elizabeth Kramer:

Hmm.

Barbara Clark:

And it doesn't mean that they still didn't need accommodations and help and that their brain was completely healed. It just meant that they actually were starting to not have some of the really extreme struggles they had had before that. And if we look at the thing where I said to cut our kids' age in half, now when our kids are 18 and entering Adult World, they're 9 or 10 developmentally, most of them, but when you're 30, if we cut their age in half, they're 15.

Elizabeth Kramer:

Mm-hmm. That makes a lot of sense.

Barbara Clark:

...that it just--it actually kind of fits. So, there is a lot of hope, but it's a lot of hard years, but those years will be less challenging if we start to reframe and use trauma-informed parenting strategies that focus on connection and relation and move away from consequence-based parenting, and that's what you'll hear in some of the other trainings that are on our website or that we're happy to do for you guys, is using different strategies. Consequence-based parenting for the majority of kids with Fetal Alcohol is completely ineffective and actually causes further trauma to them and damage to the relationships with their family.

Elizabeth Kramer:

Excellent. Important, then, to know and to get a good diagnosis and know what you're dealing with so that you can employ the right parenting strategy. Barb, thank you so much again. Really, some fantastic information here. I'm seeing requests for additional trainings on this topic and I know you and I talked about it before this started, so, hopefully we'll collaborate in the future, but we will definitely send resources out to all of the registered participants, which you all are welcome to share with your colleagues as well. And Barb, I see you've posted the NACAC website and specifically the FASD section of that website. That is a fantastic resource as well, so, I would encourage everybody to check that out for more information. But thank you, thank you, thank you again, and I would just thank also our audience for participating today and encourage you all to fill out the survey and give us some feedback.

Barbara Clark:

Thanks, everybody.

Elizabeth Kramer:

All right, you all take care. Have a great afternoon. Thank you.