Prenatal Alcohol Use and Fetal Alcohol Spectrum Disorders (FASDs): What Healthcare Professionals Need to Know

Sarah Brown: Hi everyone and thank you so much for joining us today. My name is Sarah Brown and I'm the Director of Program Services with FASD United FASD United is the national hub for Fetal Alcohol Spectrum Disorders, or FASD. We are committed to uplifting, empowering, and supporting individuals and families who have been impacted by prenatal substance exposure. As part of this work, we are very grateful to be a part of the CDC's NPN. The NPN stands for the FASD National Partner Network. The NPN, funded since 2022 by the CDC, is composed of eight national organizations that build an interdisciplinary clinical collaborative framework. The framework contributes to reducing prenatal alcohol and other substance use, improving support services and access to care, and improving identification and health of individuals with FASDs and their families. The NPN has developed dozens of resources for healthcare professionals on the topics of prenatal alcohol and other substance use and FASDs, including practice manuals, online courses, journal articles, organizational policies and recommendations, grand round presentations, toolkits, webinars, blogs, and a, 12 part video series highlighting the stories and experiences of people with FASD. Today we're going to hear from other professionals involved with the NPN as they talk about the important work that they do and how it can influence the important work that you all do as listeners and healthcare professionals. Doug, would you like to start by introducing yourself, please?

Doug Waite: Hi, I'm Doug Waite. I'm a developmental behavioral pediatrician. I work in Manhattan.

Sarah Brown: Thank you so much. Roxanne, would you like to go next?

Roxanne Chang: Hi, I'm Roxanne Chang. I'm a general pediatrician in Los Angeles county and, representing the American Academy of Pediatrics today.

Sarah Brown: Thank you so much. Roxanne. Sandra.

Sandra Gonzalez: Hi, Sarah. I'm Sandra Gonzalez. I'm an associate professor and mental health clinician at Baylor College of Medicine in Houston, Texas. and I am representing the Medical Assistant Partnership for Healthy Pregnancies and Families, which is a collaboration between the American association of Medical Assistants and the University of Nevada, Reno. Pleased to be here. Thank you.

Sarah Brown: Thank you. And last but not least, Jeff.

Jeff Quinlan: Good afternoon. I'm Jeff Quinlan I'm the Chair of Family Medicine at the University of Iowa and I am representing, the American Academy of Family Physicians.

Sarah Brown: Thank you all so much for being here. let's start by setting the stage. We're here because it's Alcohol Awareness Month. Can you tell us why is this conversation so important?

Doug Waite: This is a really important topic because we know that so many, people in general drink, alcohol because it's a legal substance and it's part of our culture. At the same time, we also know that about 50% of women use alcohol when they're of childbearing age. We know that there's a high risk of exposure to the baby that's developing the baby's brain. Alcohol. Alcohol is a neurotoxin that affects brain development, just like lead kills brain cells

Roxanne Chang: and it just has lifelong implications. and I'm also here, I think it's important to discuss because it is so misunderstood, it flies under the radar. we don't have the level of public awareness that we ought to about it. I was just on an IEP meeting yesterday for a child who was pre, prenatally exposed, who has actually FAS, Fetal Alcohol Syndrome, with the physical features present. And, the special ed administration was asking me, so is the relationship between alcohol and cognitive, issues that this particular child was experiencing, you know, is that an association or is that a cause? So I think much of our public and, you know, the individuals who are working with our kids in all of these various systems still don't understand the impact of alcohol on the developing brain and what that looks like in different spaces, especially in our educational systems as well.

Sandra Gonzalez: I think, for me what really stands out is the importance of, early education and awareness. So I want to start off by, noting not only the importance of understanding what may occur if baby, is exposed to alcohol in utero, but also to highlight the fact that alcohol exposed pregnancies and FASDs are preventable. So the key is that, alcohol is avoided at any stage of pregnancy, including before the pregnancy is even recognized. we know that about half of all pregnancies in the US Aren't planned. So early education isn't just for someone who's actively trying to get pregnant. It's for anyone of reproductive age. So if we can get that message out publicly, we engage in true prevention.

Sarah Brown: Absolutely. Thank you so much. Oh, Roxanne, did you have a point you wanted to add?

Roxanne Chang: Oh, I was just going to jump on. Sandra mentioned early, you know, intervention. And that's so important for kids, whether or not we know that they've been exposed. But to have that radar for identifying signs and symptoms of fasd, because we know the literature shows that early identification, early intervention matters for, for the life course. So we want to get the message out there to get the recognition, of affected kids and to get them the help that they need.

Doug Waite: And I would add that this is often described as a hidden disability, which Roxanne and Sandra also alluded to. Which means that many times these children fly under the radar at schools and in society because, because they might have normal cognitive, learning ability, but they really trip over themselves and can't get through the day when you look at adaptive function, their ability to do day to day, age appropriate tasks. And for that reason I think parents end up having to be the strongest advocates trying to explain what's going on with their children in the face of people who think that their child could do this if only they tried harder. And that's the hidden disability part of this. The other thing is we're not going to be able to identify kids with fetal alcohol spectrum disorders until we begin as practitioners screening all children for prenatal alcohol exposure. Because only 1 out of 10 kids meet criteria for fetal alcohol syndrome. All the other nine out of ten kids, you have to get a history of prenatal alcohol exposure. So it's important for all, general practitioners to begin screening for alcohol exposure. And we'll be talking about that later in the podcast.

Sarah Brown: Roxanne, you mentioned, supporting a child with FAS, which is one diagnosis under the FASD umbrella. Can you tell us more about FASDS in general?

Roxanne Chang: So as you mentioned, you just said the word umbrella. FASDs are an umbrella, term for a number of diagnoses, that have been identified to try and describe both the physical as well as the neurodevelopmental neurobehavioral effects of prenatal alcohol exposure. And that umbrella term currently in the US covers the following diagnostic categories. So FAS, Fetal alcohol syndrome, as you mentioned, partial FAS, arbd, which is alcohol related birth defects, and the most common really is without many physical findings is our arnd, alcohol related neurodevelopment, disorder, which also has high overlap with a DSM 5 diagnosis, the NDPAE, the neurobehavioral disorder associated with prenatal alcohol exposure. So when we're talking about FASDs, oftentimes we can just kind of use that term loosely to address one or more of these, diagnoses.

Doug Waite: And I, want to jump on top of what Roxanne just highlighted for me, that the gateway for general pediatricians and practitioners in general to begin diagnosing this in their practice because there is a paucity of people who feel comfortable diagnosing fetal alcohol spectrum disorders is the newer, DSM M5 diagnosis. That's a condition for further study that hopefully will be certified in the coming DSM additions. that's called neurodevelopmental disorder associated with prenatal alcohol exposure. Neurodevelopmental disorders are things like autism, intellectual disability, global developmental delay, speech delays, many of which we see within kids that have an fasd. So by saying it's a neurodevelopmental disorder and then saying associated with prenatal alcohol exposure, we're linking the prenatal alcohol exposure to what we're seeing. The brain based disorder that unfolds over the course of development and specific developmental challenges that we need to support and help families get the support they need. At the same time, I think this highlights an issue that comes up in many cases in practice where you have a child that you know is exposed to drugs but you don't know about the alcohol. And to me this gateway of saying neurodevelopmental disorder associated with prenatal alcohol exposure opens up the ability for us to say neurodevelopmental disorder associated with documented prenatal cocaine or opioid exposure. Alcohol exposure unconfirmed because as a developmental pediatrician on the front lines, I'm going to treat that child as if they have an fasd, both to educate parents, educate people who are working with this child to show how they are different from kids with autism, a isolated speech delay or intellectual disability.

Roxanne Chang: Can I add a little bit? thank you so much for that Doug. and kind of to piggyback on what you're saying, that NDPAE can be, I think is our gateway to wider recognition and therefore better supports for kiddos and families affected by fasd. The American Academy of Pediatrics has recently put out a little cartoon schematic and we really want to encourage people, primary care providers, those who are on the front lines, to recognize the neurodevelopment and the neurodevelop and the neurobehavioral symptoms of fasd, utilizing essentially, the categories that have been specified in the ndpae. and so one of the mnemonics that we have that we're trying to encourage is fasd. So F is fetal alcohol exposure. And as Doug mentioned, in certain populations we may not be able to have access to the exposure but just have that suspicion. Unknown is not the same as no exposure. Right again, unknown exposure is not the same as no exposure. So that's the F. Part A is adaptive skills deficits. So behind somewhere in their ability to navigate daily life, S is for self regulation problems and then D is for developmental delays and other cognitive learning delays. So those actually map onto the ndpae, symptom categories. And that's, I think that is if primary care pediatricians can recognize those symptoms of kids coming in, that could help us identify perhaps more kids with FASD and be able to frame the appropriate supports. And as Doug mentioned, it is different from autism. It is different from an isolated speech and language delay. And those differences are important because

Roxanne Chang: they're really important for thinking about how we support, and that therapeutic approach to our affected kiddos. So it's not about a label. The diagnosis is not about a label, but it's about how do we frame supports for thriving.

Sarah Brown: Absolutely. And as we've been m talking about this, we've referred a lot to children and younger patients with FASDs. But it's of course really important to note that FASD is a lifelong condition. And so for those who did sort of fly under the radar and didn't get a diagnosis as a child, they might be able to be diagnosed later in life. so Jeff, can you speak to that lifespan perspective?

Jeff Quinlan: Because, the diagnosis of fetal alcohol syndrome and fetal alcohol syndrome disorders really relies on often early in childhood, the knowledge that the mother had used alcohol during pregnancy. You know, those tend to be a little bit easier. unfortunately you don't always know that. And sometimes there's milder cases or sometimes misdiagnosed cases that would present, you know, in adolescence and in adulthood we can see things like adhd, depression, anxiety, are common things that you'd see as adults that unless you really delve into it and look at it, you'd miss that this was part of an fasd. And so I think that's a common place where I would see it. I think some of the common things like growth delays and the facial dysmorphologies and some of the nervous system findings, those tend to occur earlier in life and they typically are picked up earlier. but depending upon what care an individual's had available to them themselves, early in life, they may not have gotten, you know, coordinated care to allow for that diagnosis. And so sometimes that can delay until late adolescence and adulthood as well.

Sarah Brown: So in addition to the absolute importance of identifying individuals with FASD and giving them the evidence based, meaningful supports, there's also a prevention piece, that we can talk about. So, alcohol exposed pregnancies are often preventable with education and meaningful supports and awareness. Can we talk more about the

Sandra Gonzalez: prevention approach I think I'll take this one mentioned earlier the importance of education and awareness, really being the foot in the door that we have in our conversations with patients when they come in. Another important piece is universal screening. So rather than asking close ended questions like do you drink alcohol? Or screening based only on who you think might be at risk, it's important for all of us in healthcare settings to implement m a universal screening process. So an evidence based intervention like alcohol screening and brief intervention or alcohol call sbi, should be a standard of care for every patient because that's the best way to identify individuals whose drinking may be putting them at risk for a host of consequences. So could be health, could be social, could be legal. so when a provider asks about alcohol use routinely, just like they check blood pressure, it normalizes screening and having conversations about patients alcohol use. So it's not about targeting anyone, it's not about judging, it's about a quick evidence based check in that identifies early risk for everyone. So research shows us that just a few minutes of a brief intervention can significantly reduce alcohol exposed pregnancies. And for all of you clinicians listening to this is really a small time investment with a massive return for maternal and child health. and as a social worker by training, I have to say none of this works without compassionate support. So if a patient feels even a hint of judgment, the door to open and honest conversations close. So we have to approach these conversations in a non judgmental manner, creating a space where a person feels safe enough to say actually I've been struggling with this or I didn't realize I was pregnant and I've been drinking. So when we swap shame for these supportive resources and clear guidance, we strengthen the relationship we have with our patients and it gives us an opportunity to intervene earlier.

Doug Waite: I think that's a really important point Sandra. And one of the things ways that somebody that I often present with for the AAP describes this and she's a mother who has a child who is in her 30s now, has the overall ability of about an eight year old. And she describes this as I'm not a pregnant woman who decided to drink to hurt my baby. I'm an alcoholic who became pregnant. And this you know, period of time, especially before a woman discovers her pregnancy, really offers us as practitioners the ability to begin screening for this. Acknowledging the degree of stigma that goes along not only with alcohol use, but especially alcohol use by women and even more especially alcohol use by pregnant women. And One of the ways I like to do this is by asking when, a mother discovered her pregnancy, did she have any medical problems during her pregnancy? Was she prescribed any medications during her pregnancy? And then how much alcohol did she drink before she found out she was pregnant? Not did you, but how much did you drink? Because, again, it normalizes alcohol use, because we know how common this is. And then how much did you drink after you found that you're pregnant? Once you start asking these questions, one, you'll find no one comes back at you with an attitude and asking, why you're asking me that? Because you're so used to asking this, they're going to feel as comfortable responding as you feel asking the question. Just like we screen for suicidality. So this becomes a normative question. The second thing is you'll be surprised how many times you find out the degree of alcohol use before a person found out they're pregnant, in addition to many disclosures of how much they used after they found out they're pregnant.

Roxanne Chang: And I really do think pregnancy is a touch point. I've worked with pregnant women around the perinatal period, and this is. There's a different motivation if they do have use disorder, to seek the type of, you know, interventions and treatment that they need, to overcome alcohol use disorder or other substance use disorders. And in fact, the acog, the American College of Obstetricians and Gynecologists, has recommended universal screening for all pregnant patients coming in for prenatal care at the onset of prenatal care and certain other time points each trimester, and then, you know, additionally. But to screen universally for prenatal, substance and alcohol use. and use doesn't necessarily mean disorder. Right. on the other. On the flip side, you know, after the baby is born, as Doug was mentioning, we ask those questions. And again, that's a universal recommendation from the American Academy of Pediatrics. It's part of, well, child care to ask these questions at newborn visits, at, infant visits, and then anytime we're facing a child who's, got some developmental or behavioral concerns, to ask these questions about exposure. And if we can do that in a very compassionate way, in a normalizing way, in a universal way. Right. hopefully we can identify more. And again, it's universal because universal means that we're not picking out specific populations. You know, we're not asking people based on their socioeconomic status, their involvement with child welfare, or the color of their skin. But it's universal meaning that it's equal across the board and there's no, in that way we're trying to lessen any sort of, sort of stigma or inequitable practices. and also when we think about exposure with unplanned pregnancies. So again, it doesn't have to be use disorder. It's just people going about their everyday lives, right, not realizing that they're pregnant. Last week I think I had a couple of moms say, gosh, their pregnancy tests were actually negative and they weren't planning to become pregnant. But every person's body reacts a little bit differently. And there's a lot of cases of unplanned pregnancies and then late discoveries because of, you know, differences in body functioning.

Doug Waite: And I just wanted to jump on that, because you know, the people that Sandra's describing, you know, screening for within the obstetric population, pregnant women, you know, we know that brain development after conception is the first thing that develops before the heart, the lungs and everything else. Our brain is the first thing that develops. And brain development is a midline process. It starts as a little tube that then grows into the brain. And the parts of alcohol that most affect kids that are exposed to prenatally are the front part of the brain, the frontal cortex. That's kind of like the person that helps us get from point A to point B. It's called executive function. And so we see a lot of emotional behavioral dysregulation. kids often present with speech delay. They often have markedly hyperactive behavior. So most of them are diagnosed with attention deficit hyperactivity disorder because of the dysregulation and often overly friendly social interactions they have. They're commonly diagnosed with autism, but they so called outgrow autism. But as Roxanne said earlier, they're a little different than autism. And I want to also emphasize that as kids get older and our age related expectations go up for what a child should be able to do. The adaptive function, the part that helps us get through the day, becomes more and more, obviously impaired. So we might look at a kid when they're two or three and they kind of fit in except for hyperactivity. But this is the beginning of a course that tends to become worse with time. And I think that's important for parents to know because we might try medications to help address things like ADHD or aggressive behavior. But medications we know in kids with FASD aren't always that effective. The main treatment is environmental supports. And so if you fast forward this toward adulthood because we know this is a lifespan disorder. It's a, brain based disorder that affects us throughout our lifespan and unfolds over the course of development. many kids have what we call an intellectual disability equivalence. They have normal learning and cognitive ability. On their IQ tests they're normal to borderline, sometimes even higher than that. But when you look at their adaptive function, which rarely is measured by schools and people who go for a neurocognitive testing, that's the part where you'll see the impairment. So there can be like 18 going on, like 8 years old. And you can't expect an 8 year old kid to go out into the world, work, pay their rent and not end up, losing the kinds of things that are their structure for support. So we need to build these things from very early on. We have to educate parents and people that are supporting that child's development because this is going to probably get more and more challenging.

Sandra Gonzalez: There are several, myths and misconceptions out there. one of the most common is the myth of the idea that, because a previous child or a relative's child turned out fine, quote unquote, despite the fact that they were exposed to alcohol in utero, that somehow that means, it's safe to drink. Right? The reality is, and I think Doug was sort of talking a little bit about this, every pregnancy is unique, right? So alcohol metabolism varies between individuals and even between different pregnancies for the same person. So alcohol can affect one fetus differently than another. there's also, a myth regarding timing. So some people have been told that alcohol is only dangerous during the first trimester or that it is safe, once the basic organs have taken formed. but the reality is fetal brain development occurs throughout the entire duration of a pregnancy. So alcohol exposure can disrupt brain development at any stage, including the very early weeks before a person even realizes they're pregnant. and then something I hear, in the context of both, excessive alcohol use and people who are thinking about becoming pregnant is that, societal norms also create myths and misconceptions. So some people receive anecdotal advice, unfortunately sometimes that has come from professionals, that has suggested that an occasional glass of wine or light drinking is harmless. or I've heard a beer or wine doesn't count or it doesn't do the same harm as hard liquor. but what we do know is that there's no known safe amount, no safe type of alcohol, and no safe time to drink during pregnancy. so those Studies that you might see or information that you might get, suggesting that light drinking is fine often fails to account for long term neurodevelopmental outcomes that may not appear until that child, is out of school age.

Sarah Brown: Thank you all so much for helping us, you know, get a better understanding of prenatal alcohol use, the complexities of why somebody might have an alcohol exposed pregnancy, the impacts of an alcohol exposed pregnancy and how we can work together to support safer pregnancies. while we all have a role to play, you know, whether you're the general public or family member, healthcare workers certainly have their own unique opportunities and strengths when it comes to this work and the influence that they have. Can you speak to what a patient's journey might look like through the path of healthcare workers?

Jeff Quinlan: I think, you know, the most important thing is really destigmatizing, both you know, FASDs and then you know, the treatment that these individuals need and so making sure that from the first person who interacts with the patient when they walk into the door to the last person as they're leaving again, that they're being treated with compassion and respect. and that we teach everybody on our team m ways to interact and things that they may see in patients that have FASDs. You know, it's interesting, we often will do that for folks who are, you know, fall risks. You know, a lot of education there and we give them yellow wristbands that say that they're a fall risk. But a lot of times folks with other disabilities like an fasd, we don't necessarily call that out in any certain way and we don't always provide the education that we should be providing. And so having learning sessions within your clinic can be really helpful and focusing and you know, with the upcoming Alcohol Awareness Month, it's a great time for clinics to put a focus, ah, on this topic in their hometowns.

Sandra Gonzalez: I've had the pleasure of working with medical assistants for the better part of my nearly 32, two years in healthcare, occupying various roles throughout that time. and I can tell you that medical assistants are instrumental when it comes to having a role in preventing alcohol exposed pregnancies because they're usually the first friendly face a patient actually talks to so they can actually kick off those universal screenings in a way that feels like a normal person, part of the rooming or check in progress rather than some big scary interrogation. and they really set the stage. They're Keeping things non judgmental from the start of the visit. And in that they can build the, kind of trust that makes the patient feel safe sharing their concerns about a whole host of health related behaviors, including their alcohol use. So those mas are the ones catching the details. They're clearing up those myths and misconceptions we talked about and they're making sure that the patient actually feels supported and heard before the doctor, even walks into the room.

Doug Waite: I wanted to just jump in here because I think that Sandra brought up an important thing. I mean we've been talking about stigma, during pregnancy, but many parents, when you bring up a diagnosis of fetal alcohol spectrum disorder, about worried about stigmatizing their child. it's an unfortunate name that we have the fetal and the alcohol in there because those themselves carry so much stigma. But I would argue, I mean I came into this field, after working in foster care for, for 20 years and seeing kids that had progressively more challenging behaviors despite nurturing caregivers. And we know that FASDs are more common among children in foster care and adopted children as well as children in the juvenile justice system that get involved with the police at a very early age. but I would argue that the kids that we're talking about are kids who are already being stigmatized. And so school and beyond as kids who are bad kids, they're acting bad. And to me, many of the kids that I take care of who have an FASD school has been traumatic because from kindergarten on they basically had their heads banged against the desk. Why can't you do this? Why aren't you trying harder? Why aren't you paying attention? And I think eventually they stopped going to school and give up. Just the way if we had a boss who was yelling at us all the time, we'd stop going to work and quit our job. So I think this highlights the need for support. It highlights the need for understanding of the challenges that kids and their families have and trying to build services. Because unlike autism, where I can make a diagnosis and everything unfolds with FeSD, it's cobbling things together with what we got. And so in many cases these kids have had recurrent psychiatric admissions, and people have missed the boat. So one of the things I hear from families all the time, I've been to thousands of doctors and no one has been able to tell me how to help my kid. And that gets back to what we were talking about earlier, that this is a so called hidden disability.

Roxanne Chang: I couldn't agree with you more. Doug this is a huge issue and this is why we have to bring it to the light. kids are actually stigmatized and traumatized more when their difficulties are misunderstood and not supported. at the end of this long journey when we're able to work, when we're able to actually make a diagnosis of FASD or suspected fasd, provisional FASD words that we can tack onto the FASD if they otherwise fit the symptoms and the clinical criteria but we just may not have the robust prenatal history, in spaces like child welfare involved. kiddos. it's helpful for the kiddos to understand that self, it provides them with a level of self understanding that it's not because I have these moral failures but because their brain is built differently and also highly highlighting their strengths. It can give relief to parents and caregivers. Right. That it's not because I have a parenting problem. I've met so many parents who have been told it's because they're, they're poor parents that the children are you know, not behaving well. so once we kind of get, are able to make the diagnosis and of course work through journey with the parents through what it means to have a potential lifelong disability, there is a grief and a loss there and it's our job as professionals to journey with them through that grief and loss of having a developmental disability. But at the end of the day it gives them a better picture, it gives them a way forward. Right. And it actually starts to take the blame off of the parent and the child and to really focus more on these are brain based differences. Now let's see how we can change the expectations and the environment around you to help you thrive, to help the whole family be in a better place. And part of the stigma is also how we've been characterizing fasd. so it's beyond the pregnancy, the prenatal piece, but it often does get tied with our special populations with negative life outcomes. And sure we did have to probably message that the public health issues to get kiddos and families more support. But at the same time we can probably start tying it to more positive and strengths based aspects. And I will say that the kids with FASD that I work with, they're some of my favorite patients. they are fun, they are so social, they love to please, they're creative. Many of them are also very visually creative and I have a collection of artwork of my patients with fasd. and the families are resilient and many of these strengths are now being studied in the literature. And if we can talk more about the strengths too, maybe we can m make a dent in the stigma and the trauma that's been associated with FASDs.

Doug Waite: I totally concur Roxanne. I mean one of the kids that I just heard from Yesterday was an 8 year old boy who was adopted by his aunt who's a police officer in mid Long Island. And the first time I saw this kid it was during the COVID pandemic. He slid down the banister of the stairs and landed right on his feet at the bottom of the stairs. And right now he's 8 years old and he's state ranked in gymnastics. The coach says he's never seen a kid like this and that is going to give this kid self esteem. Despite challenges with social interaction, impulsivity, all the things that attend this. And I agree with Roxanne, these are wonderful kids.

Sarah Brown: I really love that you brought up using a strengths based approach and looking at each of your patients as individuals with their own unique strengths and support needs too but things that bring them joy and dreams. and all of these things that health care professionals often get to learn about the patients that they're meeting with. we hear from people with FASD and we talk about what would be most helpful in supporting them. There's a theme that really just comes up time and time again and that's access to a healthcare worker, whether that's a doctor or a nurse or a medical assistant or a mental health clinician who knows about fasd, someone who gets it, who treats them with dignity and respect, who works with them to address their health and support needs in ways that are empowering and non stigmatizing which y' all have been speaking to. And I just want to add, you know the research backs that up. and it, it really speaks to the importance of today's conversation that the more that healthcare workers learn about FASD and the variety of ways it can present and impact a person's life, the better they could support their patients. So I just really appreciate that, that sharing of the individuals and, and what that's looked like in discussion with people with fasd, we also frequently hear the need for more FASD informed services and supports in general. So not only in healthcare but across fields like education, which Doug has brought up, and across the nation. So in 2025, just last year, advocates worked effortlessly to help pass major legislation called the FASC Respect Act. and I just want to tell you about it because it's really impactful and exciting. M It marks the only significant Federal update to FASD policy in nearly 20 years. the law modernizes the federal approach to FASD by reauthorizing programs focused on thoughtful prevention, improved identification and diagnosis, and education for providers and the general public. The new law also encourages coordinated action on the state level. as the Secretary of the Department of Health and Human Services is directed to award grants to build state and tribal capacity to prevent prenatal alcohol exposure and limit adverse life outcomes. for healthcare providers. The Respect act authorizes the strengthening of diagnostic services, improves provider training, and supports research on culturally and linguistically appropriate interventions. So all things that we've been talking about throughout the discussion and now there's actually legislation and then some federal funding to support those initiatives. So really exciting to see, that work coming together to continue to support, you know, how we're identifying, treating, supporting and uplifting people with FASD. passage of the Respect act provisions authorized $12.5 million a year through fiscal year 30. But this funding does still need to be appropriated by Congress. So healthcare professionals and organizations can play an important role in ensuring the sustainable implementation of the FASD Respect act by advocating for funding increases and making sure that their state agencies are educated on the new law so that those things are actually happening and we're seeing them influence the work that we do, whatever communities we reside and work in. Another important way that we can all better support people with FASD is by reducing stigma. We've touched on that a little bit, but, can you share more about what does it look like to take a non stigmatizing approach?

Jeff Quinlan: For me, when I think about reducing stigma, it starts really in the preconception period. so, there's a lot of stigma obviously about alcohol use in pregnancy for good reason. M But if we just pick pregnancy and the beginning of pregnancy is the first time that we're talking to our patients about alcohol use, it can be really stigmatizing. So making sure that we're screening all adults, for alcohol use and alcohol use disorders on a regular basis so that they're used to us asking them those questions and they get used to answering those questions honestly and that we're able to provide responses to them, that again are compassionate and appropriate can really help decrease the stigma there, make an earlier diagnosis and then hopefully during pregnancy we can help decrease, the number of, infants that are exposed to alcohol and reduce FASDs overall.

Sandra Gonzalez: Thank you, Jeff. for Me when I think about ways that we can reduce stigma. A very simple way is by everyone in the practice in that setting using person first communication. So we want to use behavior focused language. Things like a person who drank during pregnancy versus an alcoholic. Right. Because we know that if we use labels, that often increases shame. I also want to remind people about the importance of trauma informed care. Many who use alcohol during pregnancy are doing so because they're experiencing high stress or they have a current or past history of trauma. So we really need to approach patients with empathy and validation rather than blame because that improves trust, and encourages engagement with prevention or treatment services. So I always recommend a conversation starter like what's going on in your world. Right, because that's leading with that empathy and validation. and that trust that's built as a result can help us to get people into the supportive services that they actually need. and this is really a system wide responsibility. stigma reduction is a shared duty, across the entire healthcare system. Every single staff member plays a role in maintaining a supportive, stigma free environment at, at every patient touch point. So if we can replace judgment with curiosity and support, we're going to see much better outcomes for everyone that's involved.

Sarah Brown: Beautifully said Sandra, thank you so much. A lot of different ideas and suggestions have been shared throughout today's discussion. What are some major takeaways that listeners should leave with that they can implement in their practice?

Doug Waite: Practitioners should screen all children for prenatal alcohol exposure. Without that history of prenatal alcohol exposure, our children with an FASD will go undiagnosed and this will continue to be kids who are mislabeled, mistreated and not supported in their development.

Sandra Gonzalez: prevention isn't just a one time talk. it's a full spectrum of care from preconception counseling to routine check ins. also important to note that it's never too late to stop. If someone stops drinking at any point in their journey, it improves the health outcomes for the baby. So every day without alcohol is a win and we need to celebrate that progress.

Roxanne Chang: Along with universal screening, I would say, is to recognize the signs of fasd, so be familiar with what those signs are. we look for what we know. So if we don't know something, we're probably not going to look for it. so that piece of educating our frontline providers is really, really important.

Doug Waite: And I wanted to add that the only reason for making a diagnosis is intervention. So suspecting and diagnosing a fetal alcohol spectrum disorder or neurodevelopmental disorder associated with prenatal alcohol exposure is the beginning of trying to put supports in place. And without those supports and recommendations the diagnosis is just a word.

Roxanne Chang: Absolutely. And like we've mentioned before, diagnosing is not to stigmatize and label, it's to get the proper supports in place for thriving and for wellness. I do want to mention something about referral pathways and thinking about how we actually do the supporting. Right after we've maybe identified or suspected. and as we're rolling out education and getting frontline providers more aware of presenting signs and symptoms of fasd, what I've run across is oh my gosh, I now feel overwhelmed. Most of us probably don't live near an FASD diagnostic/treatment center. What do I do now? and so I just want to encourage everyone that we can all do something in our own little space. Whether it's me alone or a couple buddies that maybe are like minded. but that advocacy piece of who we are as clinicians, right. I always think of advocacy as see a need, meet that need. and we can do that at a very grassroots level. I've learned so much from working with our friends at FASD United, also with some of our grassroots California legislative efforts. You don't have to have a huge grant, you don't have to have like some major university name behind you to start doing things. And so what we started doing in LA county because we were running across just too much need and not enough capacity. And I as a pediatrician in a low resourced county hospital was dealing with a lot of fasd. I could identify them but now what do I do? we need FASD adapted supports, therapeutic treatments, mental health. Like how do I interface with all of these other places and spaces that we need better understanding to support our kids and our families. And so it was literally just, I reached out to some friends in mental health and we started a telehealth, a teleconference collaborative every month. This is not backed up by by any sort of, you know, grant funding or anything. It was just, it just started off with reaching out to friends. Let's get into a professional space where we could talk about some difficult things, where we could do warm handoffs, where we could share resources, information. And since then it's grown. so I would encourage you like you're never actually alone. There's of course our national eight, our various national agencies. FASD United is a great resource, AAP aafp, we have champions from all of these places, but more locally, all you have to do really is reach out to some like minded folks and see what happens next.

Jeff Quinlan: there's a number of resources that have been developed over the last decade or so by not only the afp, but other partner organizations that look at both the identification and the treatment of FASDs. And those will all be located on the website. following this podcast and for

Sandra Gonzalez: one last takeaway today, something that I say often, when I'm doing trainings or when I'm talking to my colleagues and really spreading, the message around prevention of alcohol exposed pregnancies and FASDs. There is no safe amount, no safe time, and no safe type of alcohol during pregnancy.

Sarah Brown: Thank you all so so so much for this excellent discussion. I really appreciate each of you taking the time to share your insights, your skills, your lessons learned. Thank you to our listeners for your interest in this subject. The work that you all do is so important and the fact that you're using your time, your limited time to learn more really shows just how deeply you care about the people that you work with and support. and together we truly can build an FASD informed world. Thanks again everyone.