

Lyn McMurry 00:11

Welcome to the LDA podcast, a series dedicated to improving the lives and education of all learners. This week we talked with Lyn McMurry and Julia Rivera from North Texas FASD Network about fetal alcohol spectrum disorder. We learn the characteristics of FASD, the connection between FASD and LD, and learn about some resources that are available to help.

Kristina Scott 00:35

Hello everyone, I'm here with Lyn McMurry and Julia Rivera, both from North Texas FASD network. The FASD network is a group of parents whose mission is to provide support and resources for parents and caregivers as they navigate through the journey of fetal alcohol spectrum disorder and increase awareness of FASD in the community through education and advocacy. Thank you for joining me, Lyn and Julia.

Lyn McMurry 00:59

Thank you for having us.

Kristina Scott 01:01

So let's just begin by what is fetal alcohol spectrum disorder?

Julia Rivera 01:06

I'll take that. This is Julia Rivera. Fetal alcohol spectrum disorder is a range of characteristics that result from exposure of an embryo or fetus to alcohol. It is not a rare disorder. Recent estimates are that it affects between two and 5% of the first graders in the United States today. So it's not something that you see once in a career. It's something that is pretty commonplace. Despite that, it is not diagnosed in the vast majority of cases. The kids may have a diagnosis such as ADHD and learning disabilities, however, they probably do not have the diagnosis of fetal alcohol spectrum disorder because it's not particularly well known. Most people have heard of fetal alcohol syndrome, which has facial markers and is associated with small in stature and a low IQ. The recent changes encompass children that fall outside that description. Fetal alcohol spectrum disorder does include fetal alcohol syndrome, but it also includes alcohol-related neurodevelopmental disorder, neurological disorder with prenatal alcohol effects, and partial FAS or partial prenatal alcohol syndrome, which is kind of an obsolete description, but still out there with some individuals and alcohol-related birth defects. The impact of alcohol on the developing embryo or fetus is profound. We have kind of a pattern that emerges, it's not really a checklist. Not every kid will have every symptom. But the characteristics that emerge are neurological, neurocognitive defects, adaptive functioning defects, and self regulation defects. They can be kind of lumped together under those general categories. As far as neurocognitive deficits, you'll see problems with executive functioning, organizing, prioritizing, initiating action, self monitoring, judgment, transitioning, general executive functioning deficits, but we also have problems with abstractions. These kids have a great deal of difficulty with concepts that are abstract, this includes cause effect relationships, and they just don't get cause effect relationships in a normal manner, predicting outcomes, having foresight, that's something that they often lack. Working memory is also impacted. Their memory is inconsistent. They have days where their memory seems to be fairly okay. And then other days where the memory is not working. It's like living in a house with faulty wiring. Sometimes you can flip the light switch on and it works, and sometimes you turn the light switch on and it doesn't work.

It's kind of an on again off again. So the working memory is problematic, slow processing speed. They take a while to process what is said to them very commonly. Again, that's a neurocognitive deficit. Learning disabilities, it is the leading non genetic cause of learning disabilities. And it also impacts receptive language. These kids are generally chatty, very good in the expressive language. But receptive language is a different story that they are limited in their receptive language. As far as self regulation, the second major category of symptoms, these kids often have trouble sleeping, they have trouble calming and resting to have a normal sleep pattern. They have trouble with their attention, they have trouble with their sensory needs, often, they're very impulsive and emotional regulation, these kids will rage, they will become physically aggressive with little or no provocation, which is puzzling and alarming to all concerned. And this is well beyond the age that you would perhaps expect that are twos or threes, you know, on up into preschool, or elementary school and even beyond, they do have problems with their self regulation. And that is a primary characteristic. Finally, their adaptive functioning, socially and maturity wise they are not at the level of their peers, our rule of thumb is that they're about half their age, that if you have a kid who for example, is 18 years old, he may in many ways, emotionally and socially, be operating much more similarly to a nine year old, which is is puzzling to those around him. Their expectations are, of course, that he will act in an age appropriate way. And, when he doesn't, that causes problems. Their daily living skills generally lag far behind what you would expect. They do have poor separation, which is a problem that is known to be associated with all sorts of brain damage, where an idea or a concept or a movement will be stuck in their heads, and they simply can't get past it. They keep engaging in the behavior or wanting something far, far beyond what is reasonable at all. These kids often have a normal to even high IQ. And yet their neurocognitive abilities, their adaptive functioning, and their self regulation skills do not match that higher IQ.

Kristina Scott 07:26

So it sounds like it goes across social development, behavioral development, as well as cognitive development. And one thing that you mentioned was learning disabilities. So is this a type of learning disability? Or is FASD co occurring with a learning disability? Can you help kind of distinguish between the two?

Julia Rivera 07:49

My understanding is it's best seen as a consequence, that fetal alcohol spectrum disorder causes learning disabilities, that is one possible result of exposure of the embryo or fetus to alcohol, it literally damages their brains. And I know Lyn will talk a little bit more about this, but it damages the brain on a number of levels.

Kristina Scott 08:15

So what happens to the brain?

Lyn McMurry 08:19

The effect of the alcohol is that the neurons are scattered in the brain through the developmental period. The neurons, because of the alcohol, the alcohol goes through the placenta into the fetus, or the embryo, the developing baby, and the neurons, then the alcohol reaches the brain, and the neurons become impacted in a couple of different ways. So neurons have a home to go to for the brain to properly function. So some of the neurons, due to alcohol effects, are scattered, which means that

instead of going to the one part of the brain where they should, they end up in another part of the brain, so it affects the function of the brain. Another way is that some of the neurons can die. And therefore the center of the brain that needs all these neurons doesn't have enough to function properly, and or the neurons might be not correctly formed. So there's all kinds of possibilities. The brain then is functionally not working at the optimal level. We know that the brain has coordination between all parts of the brain and parts of the brain that are affected in a major way is the prefrontal cortex, and that's the executive function part. So these children do not have the higher level thinking capability that you grow into and becomes a part of your thinking at about age seven, and then again, further develops at age 12, or 13. So they're very literal. And the right brain then does not coordinate with the left part of the brain very well, because the corpus callosum is greatly affected also, that is the highway that transfers information back and forth to have the right hemisphere talk to the left hemisphere. So if a child is impulsive, that can be the right hemisphere of the brain. And yet, the left part is the logical or thinking part. And if that highway is not properly connected, there is no kind of like brakes on the impulsivity. And that causes a lot of problems, because you might find that the children "steal" what we call in quotes. But it's a two concept idea. One is that it is an abstract theory. It's an abstract concept. And without that higher level thinking, they don't know that it's stealing, because ownership is abstract. The other thing is, if they do kind of recognize that that belongs to somebody else, the impulsivity takes over. And then they don't have the stop to say, wait a minute, what will be the consequences for this? So the impact on the brain is profound, it is lifelong. There is no cure, these children look normal. And as Julia said, the expressive language is superb. They talk normal, and yet invisible disability, they cannot succeed unless the diagnosis is recognized, or the disability is recognized.

Kristina Scott 12:01

Is it difficult to get that visibility recognized, and why? And how could families have more of a proactive approach when they approach their pediatrician or approach a neurologist who would be making the diagnosis?

Lyn McMurry 12:16

Well, that's one of the reasons why it is so rarely recognized or not recognized enough in our children is that FASD is a medical diagnosis. And yet, a lot of the symptoms, we call the behaviors symptoms, because when they have the behaviors, a child with the higher end of the spectrum is telling us that they're overwhelmed that they don't understand. So it's a communication. And we're in the mental health arena because of those behaviors. And the mental health professionals have not been trained in FASD because it's a medical diagnosis. So it's the silo effect that we've all heard about in these professional areas. However, with the update of the DSM-V, we are in the DSM-V, and the reason we've so wanted to be in there was to increase the understanding of FASD and also increase the diagnosis. But that process is coming slow, because the mental health community has not been trained to recognize FASD. Now the new name for it through the DSM is neurodevelopmental disorder, prenatal alcohol effects. So we've got another new name, and it is quite a complex diagnosis in that manner. Not every pediatrician can diagnose. And the issue is you hear about adoptive families, because it's much easier to tell an adoptive parent that their child is affected by alcohol, rather than a birth mother that is affected that has affected her child. However, we honor the birth mothers, we know that no birth mother wants to hurt their child and there are some other issues going on. So we'll talk a little bit about resources NOFAS.org does have a support system. And there is a Facebook page that

welcomes birth mothers as well as adoptive mothers. So it's across the whole population, across all socio-economic populations.

Kristina Scott 14:49

I don't know if this is a question you can answer or not. I was recently pregnant about two years ago and my OBGYN indicated that it would be okay if I had a drink every now and then. Is that advice that one should take or...

Julia Rivera 15:08

In short, no, there is no known safe amount, we've probably heard that before. And as little as one drink a week has been demonstrated to result in damage to the developing child. So the safe amount is zero. We would go so far as to say that, if you're a fertile, sexually active woman of childbearing age, either don't drink or use birth control, your choice, but we don't want to damage the embryo before the mother even knows that she's pregnant.

Lyn McMurry 15:47

And let me add one other point to there. The reason you don't drink during all nine months, and even when you're breastfeeding, you shouldn't be drinking alcohol or taking drugs, is that the brain continues to form all nine months. And so even at the eighth or ninth month, the brain is still forming, and you just don't want...you want to be safe and keep your babies safe. So avoid alcohol throughout the pregnancy, no matter what your OBGYN says.

Julia Rivera 16:21

Part of the problem as I understand it, is that a developing child and unborn child and even a newborn child up to about three months has no functioning liver. So once the alcohol is in there, it's very, very difficult for the child to process it. Consequently, the alcohol that the baby has in their bloodstream can surpass that of what the mother has in her bloodstream, because they just simply don't have a way to digest it properly.

Kristina Scott 16:56

That's great advice. I thank you for that. Because I know I've received different advice from my OBGYN so I might as well just ask here and clear the air. You did mention how the brain is affected. And we know the brain has some neuroplasticity, so are there strategies that either teachers or parents can use if they have the FASD diagnosis? Or if they suspect an FASD diagnosis to kind of help their children?

Julia Rivera 17:26

Absolutely, absolutely. Often, when these kids make mistakes, or behavior presents itself, the knee jerk reaction tends to be well, let's give him a consequence. Deprive him of a privilege or spank them or whatever the consequence is for poor behavior. Sadly, that does not work with these children at all, it generally backfires pretty miserably. So traditional parenting techniques often do not work with these kids. So parents who find themselves raising a child that's impacted by FASD would be well advised to do some research. And there's plenty of sites on the web that are specific for FASD children. It's good to model behavior, it's good to show them how to do things rather than just telling them. Roleplay works with them, coaching, we should be sure to mention a specific book and that is "Trying Differently

Rather Than Harder" by Diane Melvin, she established the neuro behavioral model, which is one approach in dealing with these children. And it definitely is very effective. It's certainly not the only one. The bottom line with any of these strategies, though, is to just step back and to change the paradigm to look at the child's behavior and look at the child's deficit through the lens of expected deficits, given this diagnosis, to change the expectations in light of the diagnosis, because when ordinary age appropriate expectations are placed on these kids, they cannot perform. It's not that they won't perform, which is often that perception. It's that they can't perform. They're saddled with a memory that's not working properly. They're saddled with a self regulation system that is not functioning as it should. And it's generally that they can't perform, and so adjusting one's expectations and seeing this as a disability to be accommodated, rather than behavior that ought to be corrected, is key to shifting the paradigm with these kids and finding success.

Lyn McMurry 19:55

And you mentioned neuroplasticity in the brain. Because of the alcohol impact on the brain, it has changed the structure of the brain as well as the function. And that is brain damage. Because of brain damage, they do not have the standard neuroplasticity that you would expect. So that's why the reteaching, and reteaching, and reteaching is necessary. That's why you, when you tell them one thing today and they do it, the next, they may not learn it at all. So that learning capability just is not there throughout the lifetime. And that is the frustrating part, they may have normal to high IQ. But they will not learn a lot of the social skills, even though they may be taught them because the brain is just so stagnant. And there is another diagnosis. If we don't have confirmation of prenatal alcohol, there is a diagnosis called static encephalopathy. And that means that the brain is kind of static and cannot really effectively learn a lot of new skills.

Lyn McMurry 21:18

One thing we ought to also mention is that these kids do tend to have certain strengths. There are a lot of deficits, and there is a lot of negativity associated with this diagnosis. However, these kids do tend to have some very particular strengths. And we need to use these strengths in addressing their weaknesses. They're generally very friendly. They're generally very outgoing, they're chatty, they like to talk. They're very social, they want friends, they do have difficulty keeping their friends, but they do want friends, they are socially motivated. They often have some artistic abilities, either music or sculpting, drawing, whatever, often not always music. They want to be helpful. If you tell them what to do, you're gonna get 'No, I don't want to.' But if you ask them, could you please help me do X, chances are very good that they're going to help you. So you know, instead of getting all wrapped around the axle about you've got to obey me and obey me now, it's much more effective to just back up and say, 'Would you please help me do something?' They also have grit, they keep trying long after most folks would, I've certainly seen that. In my son, he has amazing grit. They just keep on trying. And every day is a new day, which is kind of a plus, but it's kind of a minus. It's a minus because the kid may not remember how to do things that he mastered yesterday, that working memory, that short term memory is a problem. Now long term memory is generally intact. So once you get it to the long term memory, you're fine. But getting there can be a slow, hard process. But I say it's a plus and a minus. It's a minus because they may not remember yesterday, but it's also a plus every day is a new day with them. Whoever they were furious and angry with and livid with yesterday, it is gone. It is a brand new day with them. And that can be a gift. They're often very, very good with animals, they're often very good with

younger children. They're often very good with the elderly or with the disabled. So they do have some strengths. And what our challenge as parents and as teachers is to find a way to use these strengths to leverage these strengths to compensate for the kids weaknesses.

Kristina Scott 23:55

Thank you, Lyn and Julia, you gave us a lot of information on a topic that I was not well versed in at all. So I appreciate that. Do you have any other resources you could leave us with? For those that are interested in exploring this topic a little more or getting more information.

Lyn McMurry 24:10

One of the sites on the Internet that we recommend to parents or educators is some videos. They are short, they are by specific topics. There is one on teachers, Six Things Educators Should Know. They one is on what's called confabulation, that I especially like. Confabulation is when the children are thought to lie, but it is really a forgetfulness of the events or the making up of sequences because of their short term memory of forgetfulness. So, Nate Sheets is his name, just go and google Nate Sheets YouTube video FASD, he'll come up, he has a series of about 30 videos, what we like is they are short and to the point. So that's an excellent reference and more information. Also, because the resources we've already mentioned, NOFAS is probably your best go to site, NOFAS.org. There's a website by parents called Come Over To, that's www.come-over.to/FAS/ And there's so many good websites available. You can also, if you have any specific questions, email me at NorthTexasFASD@gmail.com. And I'll put you in touch with some appropriate resources.

Kristina Scott 25:49

Thank you, Lyn and Julie, I appreciate your time here today. And like I said, a topic I didn't know much about but, I feel like I'm starting to get to know more about, so thank you.

Julia Rivera 25:58

Thank you for having us.

Lyn McMurry 25:59

Thank you for having us.

Lauren 26:08

Thank you for listening to The LDA Podcast. This series was made possible by The Learning Disabilities Foundation of America. Our theme music is little idea by Scott Holmes. In our next episode, we talked to Carolyn McGuire, the director of ADD Coach Academy, and author of "Why Will No One Play With Me?" about teaching social skills for students with LD. For more resources from LDA visit ldaamerica.org