Transcript

00:00:03 Speaker 1

Welcome to season two of UBC CPD in Practice, a podcast for health professionals where we sit down with expert colleagues to learn about leading edge clinical medicine and share practical tools and knowledge you can apply to your daily work.

00:00:17 Speaker 1

I'm your host, Dr.

00:00:19 Speaker 1

Chris Morrow, Associate Dean of UBC Continuing Professional Development.

00:00:23 Speaker 1

The In Practice podcast is recorded on the traditional ancestral and unceded territories of the Musqueam, Squamish.

00:00:31 Speaker 2

Fetal alcohol spectrum disorder affects an estimated 4% of the population, yet it remains one of the most underdiagnosed and misunderstood neurodevelopmental conditions in clinical practice.

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For many, the path to diagnosis is long, inconsistent, and shaped as much by social circumstance as by clinical need.

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In this episode, I'm joined by Dr.

00:00:54 Speaker 2

Preeti Saul, a developmental pediatrician and medical director of the Complex Developmental and Behavioral Conditions Program at Sunnyhill Health Center, BC Children's Hospital.

00:01:04 Speaker 2

Dr.

00:01:04 Speaker 2

Saul is also an investigator at the BC Children's Hospital Research Institute, a clinical assistant professor at UBC.

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and a member of the Canadian Pediatric Society's National FASD Working Group.

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Her research examines how social and structural determinants of health shape the way we diagnose and treat developmental disabilities.

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There's a particular focus on equity, cultural safety, and the limits of diagnostic categories.

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Today, Dr.

00:01:32 Speaker 2

Saul walks us through what FASD is, why it's so often missed, and what primary care providers can do to recognize it earlier and support families.

00:01:42 Speaker 2

She also shares some of the harder questions her research is surfacing about the diagnosis and whether our current frameworks are as precise and as just as they need to be.

00:01:52 Speaker 2

So let's jump right in.

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Welcome, Dr.

00:01:55 Speaker 1

Saul.

00:01:55 Speaker 1

Thank you so much for joining us.

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We're excited to hear from you about fetal alcohol spectrum disorder, and we're glad you're here to share your expertise.

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Great.

00:02:04 Speaker 3

Thanks for having me.

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Yeah, it's a pleasure.

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Thought we would just jump right in and start talking about the importance of FASD.

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I know that the estimates are that maybe up to 4% of the population have a diagnosis or diagnosable FASD and that there are significant personal health and social

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Did you want to tell me about the importance from your point of view?

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Yeah, so fetal alcohol spectrum disorder is a neurodevelopmental condition.

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We know prenatal alcohol exposure contributes to neurodevelopmental deficit.

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So children's memory, language, learning can be affected by exposure to prenatal alcohol.

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And for a diagnosis of FASD, you usually need at least

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three different areas of impairment of neurodevelopmental impairment and there's a list of 12 possible areas of impairment.

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The importance of diagnosing it is really to get kids support and there are some problems with the diagnostic process which we'll talk about later but it's important to identify that and to understand that alcohol does impact neurodevelopmental outcomes in kids.

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It's important to prevent prenatal exposure to alcohol where we can and support children.

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So it sounds like it's a complex condition with significant impacts, of course, for children and patients that are diagnosed with it.

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And I like how you said the main reason is to get access for resources for kids in the diagnosis.

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Is there a definition otherwise for FSAD besides the criteria?

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Or maybe I'll say, what does it look like?

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What are the main features?

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That's the tricky part because it's a,

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conceptualized as a spectrum.

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Every kid you see is a little different, or every kid or adult who has FASD, they might have a different array of neurodevelopmental difficulties.

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The ones that are kind of most specific to alcohol exposure include memory deficit, executive function deficits are really common as well.

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So there may be co-occurring diagnoses of ADHD, and there can be kind of differences in how

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how people understand language.

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And so they might meet criteria for a language disorder.

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Those are some ways that can present.

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Also with learning disorders in reading, writing, or math can also occur.

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But every kid has kind of a different constellation of those things.

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But I would say the attention step, the executive function impairments are probably the most common and can be really, those are really areas that really need support.

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So it's very nuanced and complex.

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It sounds like cognitive and communication is a problem as well.

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So it's not just as simple as the sentinel features, so to speak.

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No, and you can make a diagnosis of FASD without sentinel facial features.

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So that makes it even more complex.

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Did you want to just describe the sentinel features for us?

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Yeah, the sentinel facial features are three features felt to be very specific to alcohol exposure.

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The first is short palpebral fissures, so that's kind of the width of your eyes, a smooth philtrum, and a thin upper lip.

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Those are the three features, which when we're doing the diagnosis, we measure all three and can measure it against a standardized tool and give it a score on whether or not it contributes to the clinical diagnosis.

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I understand that it's

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not often there or it's in the minority that it's actually there and perhaps that's why it's underdiagnosed.

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Yeah, it definitely is in the minority.

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It also depends on when alcohol exposure occurs during the pregnancy.

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And then the other thing is that you can see those facial features in certain genetic disorders as well.

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So you always, as like a pediatrician or a developmental pediatrician, we always want to make sure there's not like diagnostic overshadowing.

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that we're also looking for other underlying conditions.

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I see.

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And so diagnosis is quite complex and it's important to get it right.

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I think I understand that it's estimated only 0.1% of FASD cases are diagnosed.

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Is that about right?

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I think that's about right.

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It's hard to know like the numbers.

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I don't think we really have the best numbers because it's hard to know how prevalent it is.

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So speaking about that and the importance of making a correct diagnosis because of the impact it has, probably there are pros and cons to having an FASD diagnosis.

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That brings me to a paper that you recently published in The Lancet, asking difficult questions about FASD in the context of the child, the mother, and the systems in which they live.

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Yep.

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Let's talk about that.

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So this is an article that I'm A co-author with some colleagues, all developmental pediatricians.

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We're all from Alberta or BC.

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Many of us are or have been leads of diagnostic clinics.

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that diagnose FASD in different stages in our career.

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And we started seeing patterns in how we go about these assessments.

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And we were asking questions about what we're doing, how we're doing it, what is the impact, which is what

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led us to write this article.

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We felt it was important to share these concerns and none of them are new.

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Actually, there's a whole slew of articles in the 90s and early 2000s that touch on similar themes that we did about when kind of the first initial guidelines for FASD were being designed.

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It goes into several different issues.

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But when you think in the context of the child, we were referring to being really critical about, is this the alcohol exposure that accounts for most of this kid's difficulty?

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Are we missing genetic disorders?

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You know, when the diagnosis was conceptualized, we didn't have access to microarrays and not everyone saw a geneticist.

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So things can get missed.

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And then in the context of the mother, real concerns about the impact of this diagnosis on birth mothers and without wanting to be paternalistic because there's not the voice of a birth mother.

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as a writer in this article, but our perspectives are from discussions with many birth mothers as clinicians.

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As a fellow, 10 or 11 years ago, I didn't see birth mothers in clinic.

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And the diagnosis felt very different when you see a foster parent or an adopted parent.

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But when our child welfare system is evolving and when kids are with their mom and when mom comes and you have to give that diagnosis,

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It has a totally different feeling.

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And it's not about the feelings.

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It's about you really question like, is it the alcohol?

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Like I'm telling this woman, this is all her fault, but there's a family history of learning disorders.

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And this kid went through trauma and mom went through trauma.

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There wasn't good nutrition in pregnancy.

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Or maybe there were other substances.

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or maybe there's a history of mental health concerns.

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So you get really critical of like these diagnostic categories.

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Are they because of the alcohol exposure or are they correlated to alcohol exposure?

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Like what am I really diagnosing?

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Because when someone says I have FASD, one thinks all of their difficulties are secondary to alcohol.

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There's lots of literature showing that people diagnosed with FASD have higher rates of trauma, are more likely to be from a lower socioeconomic status.

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And it's almost conceptualized as like, that's just what happens to people with FASD.

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But I think part of what we were questioning is like, is that just who we're diagnosing?

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Yes, that makes a lot of sense.

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And the sense I get is that it's much more nuanced than just alcohol and there may be other variables, but

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The diagnosis of FASD is very hard to take for a parent and subject them to bias and stereotype and a lot of negative thoughts and sometimes variables were out of their control.

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Yeah, I think our main

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perspective was really opening up a conversation and also emphasizing, and I think this is where the field of child developmental disabilities is going of like, let's support kids based on their function, based on their needs, because it's also really hard to put kids in a box of a diagnosis when they're often multiple factors.

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Like I always tell my trainees that, you know, Occam's razor does not apply

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to developmental pediatrics because they can have ADHD and anxiety and autism, not just one of the three.

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And similarly with FASD, like if you're diagnosed with a mild intellectual disability and there was alcohol exposure and there's a genetic difference, what does that mean, right?

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And then the other point we bring up, and it was a pattern we were seeing and that was highlighted in the excluded report as well, which is a report from the representative of

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children and youth here in BC about supports for children with FASD in our province is systemic racism.

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Who gets referred to our clinics?

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And disproportionately it's children in care, children in poverty.

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or indigenous children.

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You don't see affluent families in our clinics.

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That's not because the kids aren't exposed to alcohol.

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Like what are the reasons there?

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And then there's also some literature from within like ethics and neuroethics about kind of this the omission, particularly in Canada in research.

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of Indigenous children with developmental disabilities, like most of the research pre-2022 was FASD.

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There's no articles about autism in Indigenous children.

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There's no articles about cerebral palsy.

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And then

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with our knowledge now of unconscious bias, right, of, the teachings from the In Plain Sight report, when you put that all together, it's really hard to ignore, and especially as clinicians.

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And clinicians who sometimes are told by parents, like, I do not want this diagnosis for my child.

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It's really tricky.

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It's really tricky.

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Yeah, and I see how it's critical to ask this question and it's a really important discussion.

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And as our understandings become more nuanced about the social and the biases and that it's really important to question this.

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I've also heard that questioning it is important, but there's concern that without the diagnosis, there's no access to resources because the way that our model is, if

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If you have a diagnosis, you get the resources.

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Yeah, And that's really fair.

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And I think it's really important to reassure people that we're asking questions, but we're not just getting rid of the diagnosis, right?

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We want to be really critical of how we make the diagnosis.

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We want to be as specific as we can.

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We want to make sure.

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We're communicating with families openly.

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We want to make sure that, for example, families have a choice of whether FASD is the diagnosis that goes to school or if we can use a different placeholder because that is a mother's personal information being shared with her child's school.

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And as much as

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We wish the stigma wasn't there or we can work on the stigma not being there for that individual family.

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It's still there, right?

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It's a very difficult situation.

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Yeah, it's really hard.

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BC is a bit of a leader in moving forward with trying to diagnose and care for people with FASD and that we're one of the provinces that early on had a strategic plan.

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But there is the excluded report by the Office of the Representative for Children and Youth that you mentioned, and things aren't going so great.

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What are some of the key findings there?

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You know, the key findings were really that kids diagnosed with FASD aren't well supported.

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You know, some of the issues

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were around the diagnosis and like I'm A diagnostician, so that's the part of the report that I know best, but concerns raised were around, the long wait list, which we've been working on, systemic bias, but then also after a diagnosis.

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there aren't very many supports, especially when you compare it to autism in our province.

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Yes, and as a primary care provider, I can tell you I learned what FASD was, but very little, and I didn't know how to diagnose it or treat it or support it.

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And I think that's maybe a common thing out there.

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I think so.

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And a colleague of mine was saying that sometimes when you diagnose a kid with FASD, it's almost like people don't know how to support this child or don't know how to treat it.

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And it's almost like this scary thing where I would say what's really important is that child's areas of need, right?

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So if they have ADHD, then they need supports with that.

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The most important thing is actually in the fine print when you get a report

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as a clinician and you're like, Oh my God, this report is huge.

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I can't read through it.

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But to look at those sub-diagnoses and those areas of impairment and those recommendations, actually, that's really what's going to tell you about the child.

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The diagnosis of FASD is just so broad, right?

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It doesn't tell us enough.

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We know a child needs support with executive function, but the other specific supports are in the fine print.

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Let's focus a little bit on treatment.

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I know that our listeners will want to know what they can do and maybe with respect to diagnosis and treatment and what can be done better.

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What are the cornerstones of treatment for FASD besides what you mentioned that each individual difficulty needs to be addressed and have resources?

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What are some cornerstone therapies or modalities?

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I think one of the most important things for many, many of the kids we see would be behavioral intervention, but a lot of them don't have access to it.

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Behavior analysis, behavioral intervention can be really helpful.

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And I've seen it be really helpful in kids with more serious symptoms or serious behavioral difficulties.

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What does that look like?

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Who does that?

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So that would be a behavioral analyst.

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works with the family, identifies kind of the behaviors that the child and family want to work on, and then have different strategies on how to improve their behavior.

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So if you have someone who's having emotional outbursts, you know, you look at what leads up to those.

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What happens when that outburst happens?

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What happens after it?

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And you kind of break down the behaviors to see how we can

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support kids and alter that behavior, reward it differently, and look at behavior as communication.

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Right?

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Behavior is always communication.

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Access to that is difficult because of funding or.

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Mostly funding.

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There is not a lot of behavioral therapy out there.

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It's a cornerstone in autism treatment, for sure.

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And, you know, my patients who and families with autism has find it hard to access as well.

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But then there's no public funding for it if you have an FASD diagnosis.

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Sometimes schools can get behavioral analysis, behavioral intervention supports, and that can help kids.

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The other kind of cornerstone would be around attention and ADHD type treatments.

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And many of my psychiatry colleagues who I talk to feel that a lot of their patients diagnosed with FASD kind of need different medications than the typical person diagnosed with ADHD would need.

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And so it sometimes requires some

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some problem solving, but that can be really helpful as well.

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And then again, it does depend on their areas of need.

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Is it fair to say that ADHD commonly coexists?

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I would say so, yeah.

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That's a really common one.

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I've heard this term key workers, but I'm not sure what that means.

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Yeah, FAFD key workers are available, I believe, through MCFD, but it's a resource for families whose child has a diagnosis of FAFD to tie them in with key supports.

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And they can be really supportive for parents.

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I've met several families where their key worker has been really helpful.

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in tying them into counseling or different areas of support.

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And so it's helpful, but it's probably not enough.

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And I've also heard that communication skills and communicating differently can be helpful.

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Could you describe that a little bit?

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Yeah, definitely.

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A lot of people diagnosed with FASD have a coexisting language disorder.

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They might have a split between their verbal skills, like they might be very verbose, so they're like talking a lot and you're like, oh, it's good, you know, they're chatty, but they're not actually understanding everything you're saying.

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So working on those communication skills with a speech language therapist can be really helpful.

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Or they might be not picking up on social inferences and kind of slowing down and working on those things

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can be really helpful.

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And then as a clinician, to understand that as well, that someone may be very verbose and really chatty, but we've got to slow it down and make sure they understood the information you're giving them.

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For our primary care providers out there, should they be doing screening for FASD and how would they do that?

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It should be part of if you're seeing a child with developmental differences.

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When you're getting your birth history, it's something you should be asking everyone of whether there was alcohol exposure.

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It needs to be asked in a sensitive way.

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Often we frame it as kind of before you knew you were pregnant, any exposure to alcohol or.

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That's kind of one way you can phrase it.

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I know it's so hard with primary care nowadays, but if you have a relationship with your patient, but to also know that there might be exposure, but that might not be the cause of all of the impairments in kids.

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But we should be asking everybody.

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And part of that is a public health thing too, right?

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Key to ask that question about before you knew, because I understand that can be quite common, is before somebody knew they were pregnant, there was the teratogen exposure.

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Exactly.

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And people often will be like, the moment I found out I stopped drinking, right?

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Or they found out late.

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It's just so tough for parents and they didn't even know they were pregnant.

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And then to have this diagnosis, it must be devastating.

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Yeah.

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And that's part of why we're trying to, in our program, think about how we can be more sensitive to that.

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and how we make the diagnosis?

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Those are questions to explore.

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And really, I think of FASD as when that's diagnosed, that's a multifactorial diagnosis.

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There are so many things that go into the exposure and then even how the alcohol exposure manifests.

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Like there's been a really interesting study, a twin study, looking at sets of twins and how they were being exposed to the same amount of alcohol, but one twin met the criteria for FASD, others didn't.

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So there's epigenetic factors as well that we don't understand in the degree of impairment.

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So there's no overt screening tool.

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So if a clinician suspects FASD, what should they do?

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I think for a primary care physician, it's a referral to a pediatrician.

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Most pediatricians in BC do have quite a bit of knowledge about FASD.

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Everyone's clinical practice is different, of course.

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And I think more asking about neurodevelopmental differences.

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So the alcohol alone, if a child's doing fine and there's no developmental delays, that's probably not necessary.

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But if you have concerns about development, I probably wouldn't have the conversation right away that this could be FASD.

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I would just ask about alcohol exposure in the history and note it when you refer

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to a pediatrician because could it be, could it not be?

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You don't really know.

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And then the pediatrician usually refers to the tertiary level assessment of could this be FASD?

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And so a more nuanced history for the pediatrician and the pediatrician screening for autism, screening for other factors.

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And having that conversation with parents is important.

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How can primary care providers advocate for their patients that have a diagnosis or suspected diagnosis of FASD?

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And by advocating, I mean interacting with the healthcare system and getting them the supports that they need or communicating with their colleagues about this.

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I think, supporting families when they're trying to get kids support in school.

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Sometimes, writing a letter, making a phone call can make a big difference.

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Trying to understand the child's.

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unique profile.

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So I'm going to say reading the psychology report or the development, the very long reports that developmental pediatricians and psychologists.

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Oh no, you have to read the report.

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Okay.

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You gotta read it or at least understand the bullet points, right?

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And read the recommendations because they might not be like get this blood work or do this, but the recommendations usually are very thorough and really

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give you the language and the means of what to advocate for, they can be really helpful.

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They should be really helpful that their purpose.

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With Community Living BC, some people at FASD do qualify for Community Living BC support.

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or PWD.

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So taking a look at those things and if you're, I think for a qualification for community living BC depends on the adaptive score, which is again in the psychology report, but also psychology report has to be done at a certain time.

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So sometimes they need an updated psychology to see if they qualify.

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And your adaptive score is your activities of daily living.

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So some people with FASD are really impacted and need help with their daily living tasks.

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And so they would qualify for CLBC supports.

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It's like a secret language.

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So I want to thank you very much, Dr.

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Saul, for joining us.

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That was very informative and helpful.

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We're going to post some links on the website as well for some of the resources we spoke of.

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But thank you so much again.

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It was great.

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Great.

00:26:17 Speaker 3

Thanks for having me.

00:26:19 Speaker 1

It was a pleasure.

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Many thanks to Dr.

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Saul for such an informative conversation that offers a clearer path forward in diagnosing and supporting FASD care while challenging some of our assumptions about this diagnosis.

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If you'd like to learn more, check out the UBC CPD online course on caring for people with FASD linked in the show notes.

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All right, it's time for the knowledge nuggets.

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Did you know there was a time when alcohol was considered safer than water?

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For centuries, actually, beer, wine, cider, other fermented drinks were all consumed daily all over the world, including by pregnant women.

00:26:56 Speaker 2

Beer was routinely given to children and pregnant women as infection control.

00:27:01 Speaker 2

It was the safest way to stay hydrated.

00:27:03 Speaker 2

In the 1800s, physicians commonly recommended alcohol for morning sickness.

00:27:08 Speaker 2

Oops.

00:27:09 Speaker 2

into the 1900s, pregnant and postpartum women were advised to drink Guinness for iron and strength, and hospitals in the UK and Ireland sometimes served stout after delivery.

00:27:22 Speaker 2

That would really elevate the celebratory atmosphere in the delivery room.

00:27:26 Speaker 2

Before fetal alcohol syndrome had a name, Guinness was practically a prenatal vitamin.

00:27:31 Speaker 2

It wasn't until 1973 that fetal alcohol syndrome was formally described.

00:27:36 Speaker 2

Prior to that, harm was observed but misattributed to other variables for decades.

00:27:41 Speaker 2

Now that we know about the link between alcohol and FASD, there remains many socio-cultural variables to consider as we strive to reduce prenatal exposures.

00:27:52 Speaker 2

It's not as simple as just don't drink when you're pregnant.

00:27:55 Speaker 2

For more on this important discussion, see our online course linked in the show notes.

00:28:00 Speaker 1

Thanks for listening to CPD in Practice.

00:28:02 Speaker 1

Season two of CPD in Practice meets the certification criteria of the College of Family Physicians of Canada and has been certified by UBC CPD.

00:28:13 Speaker 1

To learn more about today's episode, find related resources and references and learn how to earn Maine ProPlus credits through CPD in Practice Plus, visit ubccpd.ca/inpractice.

00:28:28 Speaker 1

Research mentioned in this podcast is listed in the show notes.

00:28:32 Speaker 1

CPD in Practice is produced by Julia Donahue with research and administrative support from Camilla Ho.

00:28:38 Speaker 1

Our original music by Andre and Michael Diacanu of Cosmic Mansions is inspired by West Coast and Amazonian medicine music traditions.

00:28:48 Speaker 1

I'm Dr.

00:28:48 Speaker 1

Chris Morrow.

00:28:49 Speaker 1

Thanks for listening to In Practice and we'll see you next time.