Culturally responsive assessments– Unraveling structural racism to support Black and Latinx youth with ADHD

Episode 1

May 2024

INTRO 00:00-00:23

Welcome to Partners for Advancing Health Equity, a podcast bringing together people working on the forefront of addressing issues of health justice. Here, we create a space for in-depth conversations about what it will take to create the conditions that allow all people to live their healthiest life possible.

INTRODUCTION
00:33-01:14

CARYN:

This is part one of a two-part episode discussing the effects of culturally responsive well-being assessments for Black and Latinx adolescents with ADHD.

One of the aims of the study is to address negative impacts of structural racism. We discussed several factors, including barriers to care, proper diagnoses,

and interventions. Our guests are Zoe Smith and Marcus Blacks, who are leading this project, and they share their experiences as well as what they are doing to ensure adolescents are seen, valued, and able to get the care they deserve.

WELCOME
01:15-02:55

CARYN:

Hello, and welcome to the Partners for Advancing Health Equity podcast. I'm your host, Caryn Bell, an Assistant Professor at Tulane University School of Public Health and Tropical Medicine.

I am excited to have our guests with us today. First, we have Dr. Zoe R. Smith, who is a licensed clinical child and adolescent psychologist and assistant professor of psychology at Loyola University Chicago. She's a health equity scholar for action and her research is focused on developing and providing community-centered mental health services for Black and/or Latin A youth and their families.

Hi Zoe.

ZOE:

Hi, thank you so much for having me.

CARYN:

Of course, thank you for being here. Next, we have Marcus A. Flats. He is a second. year clinical psychology PhD student at Loyola University, Chicago. He is a health policy research scholar. And his research is focused on examining the impact that trauma has on black and LatinA adolescents and the strategies they use to cope in order to inform the development of culturally responsive interventions.

Hi Marcus .

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MARCUS:
Hi, thank you for having me.

CARYN:
Yes, thank you for being here. Thanks for hanging out with us today. We're gonna have a great conversation, I already know. All right, so I'm gonna start with Zoe. I'm gonna ask you a question about your lab. You're the director of the Action Lab at Loyola University of Chicago. Could you share with us about your research?

02:55-06:25

ZOE:
Absolutely, so our research really focuses on providing. culturally responsive assessments and interventions focused on Black and /or Latina, Latino, Latino youth. In particular, we're focused on youth that are neurodiverse and specifically look at and try to support youth and their families with ADHD.

And so a big part of our work has been to, we recognized that a lot of the families that we work with have gone to pediatricians, have gone to even neuropsychologists and psychologists and have not gotten an accurate diagnosis of ADHD. And so, we realized that even when they're trying to work within these very difficult healthcare systems that are racist, that are biased against families, they're still not getting the help that they need. And so our focus was to be able to first develop and then start providing families with culturally responsive assessments, specifically made for and by Black and /or Latino, LatinA, Latino youth with ADHD. And so what I mean by that is we really focused on not just looking at diagnostics.

Of course, diagnoses are important. That is something that could be really helpful and really powerful. But one thing that we really wanted to focus on is valuing the lived experiences of youth and their families.

And so literally just asking questions about their lives, asking about identities, asking and listening to them. I always talk to our team about our number one priority is to make families feel seen and heard.

And our clinicians do such an amazing job of being able to make families have a positive mental health experience. Because unfortunately they have had a really long history of not having positive mental health experiences because the mental health system was not made for or by them.

And so, really our work is really focused on trying to dismantle racist healthcare systems and provide access to services that are going to be really helpful for the families and youth and being able to just ask the questions that we're not always asking.

And so things like that include, it was interesting, I had really good training on ADHD and neuro diversity. one thing that was really missing in my training as a clinical psychologist was asking about trauma and then systemic oppression.

And so those are the things that we really want to make sure we're asking families about. We ask kids about their discrimination experiences. We write that up in the report

because that absolutely informs diagnoses because how we react to an oppressive environment is often pathologized.
And so we want to put that context into the report to make sure that the families and the youth themselves aren't blaming themselves for these experiences, but recognizing this larger context that is affecting them. And it's a normal reaction to have a anger or depression or anxiety About a world that is really unfair. And so we just try to validate that as much as possible.

06:26-11:36

CARYN:
All right, so you talked about or use this word pathologizing, and I'm not sure that everybody will be able to understand what that means. Could you explain or maybe give an example of what that can look like? And really also like, what are the implications of that?

ZOE:
Oh my gosh, such an important question. So when I use the word pathologizing, what I mean is that a lot of the DSM -5, which is our mental health diagnostic system, it was created a lot by white male psychiatrists and it was really centered on adults. So it's not youth centered and it is centered on white middle to upper class people.
And so within all systems, we have the system of white supremacy. And so this assumption that if you are not acting in the way that white supremacist culture wants us to act, then we are going to punish you for that. So an example of that that often is used is like with women. It was something like hysteria or histrionic personality disorder or something like that.
And that it was just women who were like, "This is messed up that we're not equal. So let's react to that." And we decided to punish people for that, putting them into institutions or institutionalizing or making people have medication, even though this was a normal reaction to an environment that was being oppressive. And so for the youth and families that we work with, often particularly Black and /or Latina Latina and Latino youth with ADHD, they get these diagnosis of more like oppositional defiant disorder, conduct disorder, and those diagnoses are not helpful. So for those that aren't familiar with them, so ADHD is a neurodevelopmental diagnosis. It is associated with difficulties with your executive functioning.
So being able to organize, manage your time effectively, shift your attention to different things. There's this restlessness that comes with ADHD. And so sometimes kids with ADHD just really struggle to regulate their behaviors and regulate their emotions.
And so can externalize those emotions a little bit more. And we know that... black and brown youths are punished more when they're externalizing. And when I use the word externalizing, I mean acting out or being impulsive and being just so excited about learning that I just have to say the answer right now, even though the teacher didn't call on me, those kinds of things, and then we punish those kids for that. And then we teach

them, "Ooh, you have to be less than we have to be." that we our society teaches them to dim their light.
And so sometimes for the kids that are more external, but do yell out in the classroom or have really a lot of trouble regulating their bodies in school, teachers will refer them to someone or they'll say like, go to the dean, like get out of my classroom, you're interrupting everybody. And so those kids often get a diagnosis of something like oppositional defiant disorder.
And the problem with that diagnosis is that when it is, well, I have a lot of problems with that diagnosis because the treatment for ODD is not trauma informed.
It's not helpful. And really often leads to the school to prison pipeline because a lot of the treatment for that is very punitive, very behavioral, without recognizing potential neurodiversity or oppressive experiences that kids are just normally reacting to. Kids are the most oppressed people in our society, and then when we add in identities that are also systemically oppressed, like Black youth, like Latina, Latina and Latino youth, then there's like, is it additive, interactive, I guess, more so a fact of that. And so our worry and what we see in reality is that the youth that we work with, the teens that we work with have had a lot of negative experiences in school, not in negative experiences at home in the healthcare system that once they reach us and we actually listen to them, which is really not hard to do.
Like these families are amazing. The youth are wonderful, funny, amazing people. It's so easy to just sit there and listen to them and let them tell their stories.
It's pretty frustrating. And also, I'm so glad that we're able to do this, but it's so frustrating that not everyone is doing this and not everyone is just asking you how they're doing and like listening to what their life is like. I went off on a little bit of a tangent, but …

11:36-14:12

CARYN:
That's okay, I was going to ask you in your opinion, why do you think? Other practices are not listening are not allowing these kids to be seen in their full experience.

ZOE:
Racism. But a longer answer is, and I'm not trying to tell clinical psychology, because my colleagues in clinical psychology are also not doing this, and are also not doing a good job of asking these questions. And so, it's not about being a clinical psychologist just makes me like, oh, I'm going to ask these wonderful questions, but there's a lot of incentives in really systemic problems to our healthcare system. So even the best intention, best trained clinicians or psychiatrists or pediatricians, they are incentivized by RVUs, don't ask a lot of questions for, basically they have to get a certain amount of RVUs to be able to make money for the healthcare system that they're existing in.
And so the shorter the visit, the more people you can get in and you aren't incentivized to keep following up, to do a lot of behavioral health like value -based healthcare nitiatives. And so, that's a big issue. And so, another big part of our research is that we

want to change that. We want to write policy briefs and talk to insurance companies about, look, if we incentivize clinicians. So, I think for us, it would be like school psychologists, clinical psychologists, psychiatrists, potentially pediatricians, depending on what they're doing. If we can incentivize them to have longer visits, to ask these questions, to then follow up with families to see if they're able to, were they connected with a therapist? Were they connected? Did they get a 504 IEP at school? Having those follow-ups incentivized would help clinicians make time to have these really easy things to use. But unfortunately, there's so many biases in how we're trained to talk to families that we have to undo a lot of that.

And I think the fastest way to undo that is incentivize to do culturally responsive work.

14:13-16:34

CARYN:
I think I would also then ask, what difference does it makes to spend that additional time, not additional, but needed time with the patients that you're talking about.

ZOE:
They get well. They get better. They are healthier people. They feel relieved the amount of families that have cried in our office or at our feedback sessions when we finally say yes, this is what you're experiencing. What you told me you're experiencing is exactly what you thought it was, whether that's ADHD, whether that's all an additional anxiety or depression or trauma diagnosis." Families just feel like, "Yes, they feel seen. They feel relieved. They are so grateful." I'm not saying this to tout our horns or whatever the phrase is, but to toot our own horns.

But I'm saying it because then they start to get better. Even, I mean, we do so 12-month follow-up surveys. So for one year, we're following families after we provide a feedback session that includes diagnoses, recommendations, and we're seeing trends that people, even if they, some, some are not, and that's because they're really struggling and we just one diagnosis, one report can't make a huge difference, but getting connected to these resources starts to make people well and starts to make them feel better and feel seen. And it helps to the school system and community and all of these things are trying to diminish their light.

If we just like let it peak out a little bit, people start to feel better. And so, right. So to incentivize insurance companies, to incentivize other people to, I guess not people, to incentivize systems to do this, then economically our world would be better because people are well and even though I don't like curtailing to the capitalist system, they're able to then go function the way that capitalism wants them to. And so, it's just and it's a It's a positive for everyone because it's leading to that kind of culture of health that ability that while being that We're really trying to see with families.

16:35-22:22

CARYN:

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Marcus I wanted to ask if you had any comments about the things we just talked about

MARCUS:
Yeah, you had asked what is the benefit of doing longer visits and I can say as one of the primary people who provided these visits for these youth building rapport and those in that first hour or so is really really important because for a lot of these teens They're not the ones Making the appointments their parents are so they're coming to a school. They might not have heard but heard of before They're sitting on an office. They're like, where am I? What's going on? And so, and within that first hour, I'm kind of just trying to get to know them a little bit, not asking too deep of questions, but still just listening to their story and providing validation to the things that they're experiencing. And then over time, they start to open up a little bit more and more, and then they feel comfortable sharing the harder things that they've experienced.
And that informs us because that doesn't just inform maybe an ADHD diagnosis, but it does opens up the possibilities and when we can see the full picture of what these youth are experiencing, when we write that feedback report, we can put recommendations in the report that support their overall well-being and their overall functioning rather than just identifying, oh, here's some ADHD supports. Here's what you can put in a 504 or an IEP. Instead, we can say, here's some community resources for this specific things that you're experiencing. Here's some therapists in the area for the specific things you're experiencing.
Here's some recommendations for specialists, like occupational therapy, or just therapists in general. And this overall air of their general functioning and well-being really makes a difference.

CARYN:
And this is an additional follow-up question I just thought of it, but it made me think of the concept of medical mistrust, and I was wondering if that is something that you all think about and how you all have designed your work to combat what would be or could have been a situation in which medical mistrust is present and driving a lot of the clinical encounter.

ZOE:
I can start in, Marcus you can jump in whenever. So a big thing about doing health equity work is earning trust first. And so that was something that our team and Marcus included really did on our first year and a half here.
So I'm from the Chicago area. I am so proud of being here in Chicago again. It's just been the dream to be able to have a position in the city that I love and being able to support communities that I'm a part of.
And so you have to earn that trust, though. And so that means going to community events, doing workshops for community partners, for schools, for anyone who wants some support. And so when you are in community, excuse me, and working with people, you earn that trust. And then when you earn that trust, then people are more willing to say like, "Oh yeah, like, oh, I hear that you're having some difficulties with,

or your teen is having difficulties in school. Well, you know what, I just met that Dr. Zoey, and I think that maybe you should call them." It has become a lot of almost word -of -mouth community -centered, what's the word? I mean, I don't want to use the word recruitment, but kind of like that. And so you have to earn trust. And what our hospital systems, our healthcare systems, our university systems have not done is... earn that trust. And so we do assess that. So we do ask families, there's like a trust and physician scale that we do look at.

But more importantly, we're just trying to build a team that's earning that trust and having a reputation for doing what we should be doing.

And so with the term medical mistrust, that mistrust is earned. We, our racist system, the university system, the medical system, all systems, because all of our systems are built on white supremacy and capitalism, are inherently built to be racist. And so, for Black families, for Latina, LatinA and Latino families, why wouldn't you? Again, that goes back to... pathologizing normative behavior.

Why would you trust the healthcare system that kills us? Why would you trust a system that has abused and used you for so long?

And so being a part of that is something that I think about and our team thinks about a lot. They're recognizing that being a part of a university, yes, does it help me to have an office and supplies and support and being able to get the grant funding to do this work?

Absolutely. And, I have to then earn trust because no matter what university you're at, you have to kind of undo a lot of that harm. And so that's been a, yeah, I guess that's a big part of our work in trying to build back that trust. And so that is going to community organizations, supporting them in any way we can. And then also once families get here, again, like Marcus was saying, like the number one thing is we're trying to listen and validate experiences. And that helps to build trust.

22:23-24:56

MARCUS:

I think another way that we build trust is, so when I started, I was a first year grad student, didn't know a whole lot, but Zoe trained me pretty well. And there was some other fifth year grad students who trained me well as well.

But really when it comes down to it, it's being a good person in the room and allowing the child to be an expert on themselves because a lot of times children are either spoken for or their autonomy is shut down.

And so just by being a good person in the room and letting the child speak and speak with a... confidence and a knowing of themselves and what they've experienced really builds that trust because they can tell themselves, "Hey, I can say whatever I need to in this room. One, because I have confidentiality and two, because this person is showing me that they care and it's not going to go back to my school and harm you.

They're not going to turn around and tell my parents and they're not going to shut me down at the end of the day." So in treating a child like a person rather than this child who the parent has autonomy over and is making decisions over, we can build that trust

and say, hey, there are systems that do care about me. I can use these systems to get the support that I need.

CARYN:
Thanks for explaining that and giving more detail about that, especially for people who don't think about these topics. But I think it also is validating for people who don't are experiencing it. So thanks for that.
Another area that I think you all's work validates a lot of people's experiences, racism and trauma. Even thinking about exposure to violence, but there's all sorts of trauma. You know, I live in New Orleans. We are located here in New Orleans, and we had a mass shooting outside of a nightclub last night and I am right now, you know, processing what happened and just feeling those things. And then I was like, oh, I have to get up here and do a podcast on Zoom.
So I just, you know, think about youth and adolescence and how they have to process things like... trauma, like exposure to violence.
And so I was wondering if you all could explain either broadly or in detail or however you want to, how ADHD racism and trauma are linked.

EPISODE ENDING
24:57-26:32

CARYN:
Please join us for part two of this discussion where we explore the intersections of ADHD, trauma and trauma. and how they affect black and Latinx adolescents.
Zoe and Marcus shared their aims to provide culturally responsive assessments and positive mental health care experiences to support youth and their families who must navigate immense pressure and stress to receive diagnoses and care.
If you have any thoughts to add to the conversation, be sure to comment on our podcast episode page at spreaker .com or on our social media channels.
Thanks for listening.

EPISODE OUTRO
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