Chelsey B. Coombs:
Hi there and welcome to the Spectrum Podcast. I'm your host, Chelsey B. Coombs. Autism research is an overwhelmingly white field — one in which Black researchers say they experience both overt and covert racism.

This summer took an especially heavy toll on many scientists of color as protests erupted in response to the death of George Floyd, Ahmaud Arbery, Breonna Taylor, Rayshard Brooks, Jacob Blake, Daniel Prude and other victims of police violence.

Today, we're hearing from four Black women who are autism researchers about their experiences leading up to and during this past summer — and what they hope will happen next.

Mary Agyapong:
Being both black and being a woman in autism research and essentially in any sort of scientific field, you know that you're underrepresented. And I think that's one of the things that for me has definitely been one of the, kind of, more difficult things.

Chelsey B. Coombs:
That's Mary Agyapong, a second-year PhD student studying eye tracking in younger siblings of autistic children at King's College London in the United Kingdom. Her experience is something Termara Parker can relate to. She studies neural correlates of face processing in autistic people as a fourth year graduate student at Yale University.

Termara Parker:
The one thing that I've noticed like being here at Yale and also being at different conferences is that there's not that many black women that are in graduate school as well as a faculty level. There wasn't many black mentors I could look to.

Chelsey B. Coombs:
Desiree "Desi" Jones says this lack of diversity often means that Black autistic people's experiences often go unexamined in research. She's a third year PhD student at the University of Texas, Dallas. She studies intrinsic and extrinsic factors and how they influence social outcomes in autistic adults.

Desi Jones:
We really include predominantly white participants. Because of that we miss out a lot on the experiences of Black autistic people or issues that may disproportionately impact them. So I think we need to do a lot better job including the Black community in autism research.

Chelsey B. Coombs:
For example, an analysis presented at the 2019 International Society for Autism Research annual meeting, showed that a U.S. autism prevalence survey included too few Black families to

yield accurate data. The 2016 National Survey of Children's Health included only 80 Black families in 2016, and only 38 in 2017.

And the problem extends to the technology used in studies, as well. Cliona Kelly is a PhD student who studies eye gaze and joint attention at Aston University in Birmingham, England. She says most electroencephalogram, or EEG, caps, which are used to detect electrical activity in the brain, aren't made for Black hair textures, and so the EEG electrodes don't make proper scalp contact.

Cliona Kelly:
If you have a child coming in or you have an adult coming in and the researcher's kind of like, "Oh, I didn't think that you'd have this style of hair. Or I didn't know that like…" You know what I mean, then you've now got that awkward moment, which could have been avoided if you had a diverse team because people would have been there to highlight this and flag it up and say, "Hey, hold on a minute. We're not being inclusive."

Chelsey B. Coombs:

It's often up to Black researchers to bring up and solve these problems. Arnelle Etienne is a Black woman who graduated with a degree in Technology and Humanistic Studies from Carnegie Mellon University in Pittsburgh, Pennsylvania. As a student, she invented new EEG electrodes that work with Black hair. Her proof-of-concept design was published on the pre-print server BioRxiv in February this year.

But Desi Jones says speaking up about a lack of diversity can lead to harassment. She went to the INSAR annual meeting last year and noticed just how white it was. She tweeted, "Autism research has a huge diversity problem. INSAR offers workshops and awards to support diversity, but a woman of color on a panel or oral presentation? Almost unheard of. We need to do better, and yes, I am saying this as someone who is impacted by this."

Desi Jones:
I ended up getting harassed online by white supremacists, and I'd like to clarify that as far as I know, none of these people were associated with INSAR or the autism research community. They just found my tweet online I guess, but they were really nasty and saying hurtful things about me. They posted my photo and I just remember this one comment, this woman was like, "She's ugly inside and out." And I was like, what do I do about this? And this… the really tough part about that moment was that I didn't really have a community that I could go to for support or advice.

Chelsey B. Coombs:
Jones says members of the INSAR community were supportive and her advisor did everything he could—

Desi Jones:

—But you know at the end of the day, he is still a white man, and he really didn't have that experience dealing with racism or that type of harassment.

Chelsey B. Coombs:
Cliona Kelly says being one of few black researchers in a field brings other types of pressure, too.

Cliona Kelly:
I think what's difficult is that feeling of knowing that the moves that you make may have, or will have, an impact on the next black female to come into this lab or the next black female for other researchers to come across or for a participant to come across. I've got this extra pressure. I've got this need to be not just good, but I need to exceed that in order for people to appreciate what I'm doing and who I am and why I'm here. And I think it's only recently that I've kind of been like… Okay. This is getting heavy. This shouldn't be a load that one person needs to take on.

Chelsey B. Coombs:
Black researchers say police killings of Black people have added to that heavy load.

Desi Jones:
After George Floyd was killed, I basically had an entire week where I just couldn't work. And I just couldn't... I couldn't focus and I just kind of laid in bed and it was really tough.

Termara Parker:
I think in academia, we're always like taught to just to be productive and to just keep going, keep working. So when we have these current events that happen, it's really hard for us to really like take a step back and like really reflect because we also have the same expectation of produce science. But we have to make it so that we can do both. You can still produce science but also still be able to really understand what's going on in the world. Because if we don't, I feel like we're not doing our job.

Mary Agyapong:
It's important for people to realize that we are human as well in terms of, you can't just sort of turn up and keep doing things business as usual if all of this emotional and racial trauma is weighing on us day in, day out.

Chelsey B. Coombs:
So Kelly decided to interrupt business as usual and bring up anti-Black racism this summer, even though it felt hard to do as one of only two Black people in her lab.

Cliona Kelly:
I said, “Look, okay, we're having this meeting but we all know that this is going on in the background. Let's talk about this.” It does feel like you're bringing that conversation there and seeing, “Okay. Can we can we go there, can we do this?”

Chelsey B. Coombs:
Though most Black neuroscientists are isolated in predominantly white departments, many reached out to find each other this past summer. Angeline Dukes, a PhD candidate at the University of California, Irvine, helped spark the idea for an online community called Black In Neuro. Dukes' tweet proposing the Black In Neuro community gained a ton of momentum, and with the help of 23 organizers, the group hosted #BlackInNeuroWeek on Twitter from July 27 through August 2 this year. It featured panels on subjects like #NeuroRacism, #BlackWomenInNeuro and #BlackJoyInNeuro. And Black In Neuro is still going strong, providing resources and mentorship for Black neuroscientists around the world. Kelly has enjoyed keeping up with the Black In Neuro Slack group.

Cliona Kelly:
I'd wake up and just scroll through the messages and it was just a beautiful environment. Absolutely beautiful just to have people who are passionate not just about science, but about neuroscience. And everyone's Black. You don't need to put on that coat. You don't need to put on that mask. You just be you. You come there and you be your original self, your authentic self.

Chelsey B. Coombs:
The Black in Neuro group has helped these Black autism researchers find each other, too.

Desi Jones:
We actually have a little group on there for autism researchers in Black in Neuro. There's fewer than 10 of us. We're all women and we have a pretty broad range of experiences even in autism research, but it's so cool to have that.

Mary Agyapong:
And I think it's something that we all really needed. It definitely made me feel like I belong in this research community and it's been great to interact with other Black people in neuro and to really kind of showcase the fact that Black people are not a monolith. There's just such a range of things that we do, that we're interested in.

Chelsey B. Coombs:
Black In Neuro has helped these researchers feel like they belong. But Kelly says institutions also need to step up and play a role in finding and supporting Black autism researchers.

Cliona Kelly:
In order for autism research to look more diverse, you need to fill the spaces with Black people. Not just for your photo shoot, not just for the magazine cover. You need these people in the background. You need that input because that's what makes the changes.

Termara Parker:

We want to emphasize that it's not just about recruitment because I think a lot of it is like, oh you're supposed to recruit more minority students, but it's more than that.

Desi Jones:
We need to increase the representation of Black autism researchers across all career levels. And we need more people in tenured positions who can serve as mentors for new students so that we can have this community aspect again. And, like, have people who can help you with these things. It's not enough though just to increase the representation of Black researchers. You have to support us once you hire us.

Chelsey B. Coombs:
Kelly says a lot needs to change. But for younger Black people who want to get into neuroscience or autism research—there is hope.

Cliona Kelly:
There is a community out there. We're very small at the moment. But we're there. Please reach out.

Chelsey B. Coombs:
Thanks so much to Mary Agyapong, Desi Jones, Cliona Kelly and Termara Parker for joining me to talk about their experiences, Anna Stitt for her work as producer, and thank you for listening to the Spectrum Podcast. You can find out more about BlackInNeuro by going to blackinneuro.com or following the BlackInNeuro hashtag on Twitter. I'm Chelsey B. Coombs, see you next time.