

Interview with Dr. Ariel Schwartz

Alex Schiwal 0:05

(Intro Music) Hi, and welcome to the MHDD Crossroads podcast where we explore the intersection of Mental Health and Developmental Disabilities. This week we hear from Dr. Ariel Schwartz at Boston University about her work with participatory action research. We hope you enjoy this episode. Thanks for listening. (Music Plays)

Jeff Sheen 0:29

How do you describe the work that you do? And then tell us a little bit about how you got involved with it?

Ariel Schwartz 0:35

Yeah, so I partner with people with intellectual and developmental disabilities and research to make sure that research meets their needs. So I think it's really important that if we're going to be doing research about people with disabilities that they are highly, highly involved in the production of that knowledge. I got into this work because I had been working with people with intellectual and developmental disabilities since I was very young since I was about 12 years old, and I came to a point where I knew I enjoyed research. But I didn't know how to reconcile my emerging interest in disability rights and the social model of disability with kind of my leanings towards science. And so after talking with some people with disabilities, I learned a lot more about this approach called participatory action research in which you partner with people with disabilities in the knowledge production process. So I come to this work bringing my lens as an occupational therapist, someone who is engaged with disability studies and has just a long history of working alongside people with disabilities, and combining all of that in a research context.

Jeff Sheen 1:46

So I'm curious what was happening for you around 12 years of age that this became an area of interest. Can you tell us a little bit more about that?

Ariel Schwartz 1:54

Yeah, so my mother was a special education teacher. She was a transition specialist and I went to work with her when I was about eight, and I kind of came away from it saying, "This is what I'm going to do. I love it." And I just went to work with her once. Right after that experience I was already going to my elementary school principal and telling her, you need to make sure that everyone's nice to everyone, we should have an assembly about disability so people stop teasing kids on the playground. It just very quickly became this, this drive within me to make sure there is inclusion and of people with disabilities in in all areas of life. And around the time I was 12, I decided that I wanted to, you know, be more engaged with population, not just be telling my principal what to do. And so I wanted to volunteer for

Special Olympics, and they told me I was too young. And I reached out to the coordinator of top soccer, the outreach program for soccer, it's a US Youth Soccer Association program. And the director in Virginia said, "Well, we don't have a program where you live, why don't you start one?" I don't know if he knew that I was 12, but we so I became engaged in that and of course, with the help of many adults started in brand, that soccer program from ages 12 to 18. And along the way, was, you know, working over the summers in therapeutic recreation. So it's kind of my entryway was my mom's work, and then sports. And then later in college, I had to really grapple with then now what to do with this.

Jeff Sheen 3:26

That's fantastic. This why I love doing this podcast because I get to hear kind of the the backstory to why people are doing the work they're doing now that we're going to focus on in a minute, but just knowing that, that you as an eight year old, were observing these things, becoming involved, and then, you know, switching at 12. That's, it reminds me of, you know, my father was in special education and it's a similar thing. This is why I do what I do now is I was exposed very early to the idea that people experience the world differently, and they should all be given an opportunity to be who they are and we can all work together to create a kind of community that everybody's included in and everybody brings something to that table. And I have learned probably far more in my experience as a professional from people that I've worked with than I've ever probably taught. And it sounds like maybe that's a similar experience for you.

Ariel Schwartz 4:18

Yeah, for sure.

Jeff Sheen 4:19

So when you when you got to college, you mentioned being an occupational therapist, was that kind of always the goal? Or did did you kind of start with special ed or how did you kind of get to where you are now?

Ariel Schwartz 4:31

Not at all. So I went into college as a molecular biology and biochemistry major.

Jeff Sheen 4:36

Okay.

Ariel Schwartz 4:36

And I was going to study the way that people with autism learned from a molecular biology perspective, and I was going to use that to help people learn better, I guess, in my mind. I love biochemistry, I kept

that nature. But I got introduced to the social model of disability and a new way of thinking about disability as a freshmen and I really grappled with it because all of these ideas about thinking about disability as something that is created by the environment, and that maybe some people with disabilities might be happy having a disability really was different for me. And I kind of felt like I knew so much about disability that this is wrong. So I really resisted it. But the more I kind of listened to people sharing this perspective and learn more about it, I realized that I needed to know more. So I ended up then also designing a major in disability studies and looking into that, but all along, it's still thinking like, Oh, I'm going to be a biochemist. I really loved biochemistry.

[Ariel Schwartz 5:39](#)

And then my senior year of school, I end up doing a thesis. It was a disability studies thesis rather than a biochemistry one, and talking with Ari Ne'eman from the Autistic Self Advocacy Network. And he basically said, "You can't you can't do the work you want to do unless you use a participatory approach. It's not ethical", And at that point in my thinking and learning about disability studies, I heard that and said, I think you're right, Ari. So that I really spent a long time thinking about what am I going to do? So, I worked a little bit in research afterwards at the Vanderbilt Kennedy Center, and along the way, was really implored to get a clinical degree. I was told that I couldn't do the participatory work I wanted without a clinical degree. And yeah, so I chose occupational therapy, because it's really philosophically aligned with my beliefs about disability and thinking about the environment. And so that's how I arrived at it and I specifically went to Boston University to work with Jessica Kramer, who had a disability studies background who was doing participatory action research. And that's how I ended up where I am.

[Jeff Sheen 6:44](#)

Well, I'm glad you you have a lot of things that I want to follow up on. I'm glad you mentioned Jessica, we're going to be visiting with Jessica and her group in a couple of weeks actually. So that'll be a nice piece and so I knew there was a connection between you and and Jessica. You mentioned so do you feel like you kind of came into this from more of a medical model, essentially, and then you discovered the social model of disability or?

[Ariel Schwartz 7:05](#)

Yeah, for sure. That was definitely the predominant model I was working with growing up. I think that, you know, I had respect for people with disabilities, but I, I don't know if I actively question the notion of cure. I don't know if I actively questioned whether or not disability is inherent to a person or or an environmentally caused or socially constructed phenomenon. So that was really eye opening for me in college.

[Jeff Sheen 7:31](#)

Yeah, that's interesting. I remember coming across Bobby Bobby Silverstein's work on kind of the core values that that I've referred to a lot of times, which is, disability is just a natural part of the human

experience. And in no way diminishes a person's right to participate in all aspects of society and then you start looking at how we socially construct so many attitudinal barriers and other kinds of barriers, and it really starts to put things in a completely different frame. So I appreciate you kind of talking about that. Can you tell us a little bit about some of the specific projects you're you're working on or have recently worked on using the participatory action research model.

[Ariel Schwartz 8:06](#)

I kind of have two strands of research. One is this methodological question of how do we do participatory research? Well, there are people doing it and but I still feel like there's this big gap and in it being scaled up, and more people being confident, we need more people to feel confident doing it. And we need it when people say participatory action research for us to know what that means for us to trust it, that it's authentic for us to trust that power is being shared. So I'm really interested in advancing kind of some methodological conceptual thinking around well, what is it when we say participatory action research for this population, and we as a field have agreed on some values, but then how we operationalize them how we make them work. So my dissertation research was around fleshing out a conceptual model for this by doing interviews with experts with or without intellectual disabilities across the world who are engaged in participatory research or inclusive research. I'm hoping in my lifetime, I'm able to do some more exciting multi site studies around this kind of a long term life goal would be that, you know, we can hand someone a toolkit, and they can feel confident carrying out a PAR project and that that PAR project isn't. So that's one thing. I'll pause, in case you have questions about one, that one.

[Jeff Sheen 9:28](#)

Yeah, no, that's a great pause, because I do have some questions. Is there a link to your dissertation or a resource that you would recommend folks that are getting interested by hearing you talk passionately about PAR that they that you would recommend they go to initially?

[Ariel Schwartz 9:42](#)

Yeah, I mean, there's there's great literature out there, I can direct you to like some of Katherine Donald's work at Syracuse University, and some work that's being done internationally. So I could cre-, I could find a couple articles that are just like good intros, and I can also share publication for my dissertation.

[Jeff Sheen 9:57](#)

Yeah, that'd be wonderful. (Music Playing)

Alex Schiwal 10:01

All of the resources that Ariel mentioned in this episode, and ones that she sent to us are linked below in the show notes. And remember that PAR stands for participatory action research in this conversation.
(Music Plays)

Jeff Sheen 10:16

You know, hearing you talk so passionately about PAR reminds me of when I started as a second year practicum student in a social work program at the University Center for Excellence on Developmental Disabilities, here at Utah State. Participatory action research was one of the first things that I was kind of trained in and had that opportunity and it's so, so nice to hear someone like yourself speaking so passionately about that methodology and improving it and, and making it more widely available and it and it brings back that's how I was kind of grounded in the work is that it's the whole mantra of nothing about us without us. And then really taking that to the next level and really honoring that throughout the entire research process, in particular, and I really have valued that perspective and I have made so many great friends and learned so much from participating in these research projects and project development groups, where all of the voices that are impacted by the project were present the whole entire time.

Jeff Sheen 11:11

I remember early on being kind of put in charge of a leadership group for young adults, and I was given an agenda of things to go talk to them about. It was basically you look young enough, why don't you go run this young adult group? And so I, I showed up and I said, Hey, this is this list of folks, this is what people want us to talk about, what do you want to talk about? And they listened to the list and they're like, we don't want to talk about any of that. We want to talk about this. And it took a completely different direction. And it was because it was driven by the people that were experiencing the things that we wanted to know about. And and it sounds like that's really you're that you're really your foundation is in that kind of model and framework, and I really appreciate you talking about it so passionately.

Ariel Schwartz 11:53

Yeah, it is. It's I'm not saying that I do it well or the best but I've always tried to learn and improve and and and get there eventually.

Jeff Sheen 12:01

So what maybe are the most impactful learning experiences you've had doing this participatory action research?

Ariel Schwartz 12:11

Honestly, I think that I came to Boston University as an occupational therapy graduate student and later as a PhD student, thinking it was more complicated than it is. And that's, that's not to say that it's so simple, but I think at the end of the day, it's, it just comes down to respect and communication and relationships. And I think people get nervous or anxious about some of the institutional red tape around it, or they're not sure how to do it. But I think I always have to remind myself like, if just think about this as sharing power in any other context and the work is making things accessible, so the power can be shared, but I'm increasingly feeling like, maybe it doesn't have to be as complicated as maybe I had been thinking it was or maybe other people have been thinking it was. So I don't know, that's something I'm newly thinking about, as a takeaway, kind of, maybe this doesn't have to be so elusive or complicated.

Jeff Sheen 13:11

Yeah, I think that's a that's a wonderful piece to add right there. I know you had a second piece and I don't want to get too far away from that. If you want to go back to the second piece that you wanted to mention.

Ariel Schwartz 13:21

Oh, sure. Yeah. So I recently was fortunate enough to have some funding from the Noonan Foundation, which is a local foundation in Massachusetts, and American Academy for cerebral palsy and developmental medicine, to use a PAR approach to develop and to conduct feasibility testing of a peer mentoring program for young adults with intellectual and developmental disabilities and co occurring mental health conditions. So in my recent experiences, working with transition age, youth, I have just watched over and over again, these young people kind of really struggle during transition age to seeing increases in anxiety, increase in depression. And the literature has supported that this is a really hard time and we're increasingly aware of the mental health needs of this population. So in our lab also had some experience around peer mentoring. And we'd been working on a project where we were hearing from folks with IDD and mental health conditions that they are feeling really socially isolated. So it seemed like a peer mentoring approach might be a way to deliver some services in a way that would be helpful to folks and, and lead to less decrease social isolation.

Jeff Sheen 14:31

Ariel, one of the things that I know that I'm excited for is in the next couple of weeks, we're going to have the opportunity about a month from now to talk to members of your team, some of the young adults that you've worked with. And I'm curious from your perspective, as a passionate advocate for participatory action research, how do you how have you experienced their involvement, benefiting yourself as a researcher benefiting the project? And then what kind of changes or benefits have you seen them experience and then we'll get a chance in a couple weeks to ask them the same type of question about their experience.

Ariel Schwartz 15:01

So their input has been invaluable from just the beginning of I, we had decided we're going to, you know, address mental health, okay, mental health is really broad and intervention needs to be more specific from that. So I had some ideas about what might make sense to address but they really were able to identify what mattered to them. So even from the beginning of what is going to be addressing the intervention they helped guide. So something big like that to things that might seem little like outcome measures, we made sure that the outcome measures we are using made sense to them that they felt they were actually asking about the constructs we cared about that the rating scale made sense. So and things like activities, we a lot of times I would develop some activities, and we trial them and they give feedback and they'd make them better or they say we don't like this one at all, you should not have this in mentoring.

Ariel Schwartz 15:52

So they were really instrumental in what the whole intervention looked like and even some on the research end of what our data collection was going to look like. So that's benefits to the research. And then it was also helpful for me to hear throughout some of the ways they were talking about mental health. I had a really, I have a really amazing colleague, I really amazing colleague, who's a social worker, who primarily works with people with intellectual and developmental disabilities. And she was able to provide me with some language in ways that she talks about mental health with this population. But then hearing it from them as well was really helpful, because that helped us figure out how we were going to talk about it with participants. And so in having a peer mentoring intervention, I think a lot of people get very concerned that a person with an intellectual disability wouldn't be able to be a peer mentor. That's kind of a big role. But if these people help design the intervention, then it really wasn't that hard for them to then go on and be the mentors because they had been so involved in it and they had a deep understanding of what we were doing. Do you have a question.

Jeff Sheen 16:59

Yeah, yeah. Let me ask you, you were talking about how maybe this isn't as hard as it as people think it might be to do this kind of participatory action research. Can you walk us through the process? How did you connect with the young adults that you ended up working with? How did you how did that whole process like, how did you recruit? How did they hear about this? How did what was their experience as far as signing up? Tell us a little bit more about the process. So that folks that are like, really intrigued by this kind of where would they start if they want to do something similar?

Ariel Schwartz 17:28

Yeah, so probably the hardest part is finding partners. And myself and some other folks who are engaged with this talk about this a lot. So I am really lucky in the Boston area to have some strong relationships with various schools and agencies. And it worked out for me to hire a group from one school. And so I got that was based on a prior relationship. So what I would really encourage folks to do is to try to form relationships with people with disabilities in the community, with organizations with

schools, because it makes it all that much easier when you come and you say, "Hey, I have a job opportunity, you're a known entity, they trust you, but also, you know who to go to." So I hired young adults from one transition program in a school around Boston. And we, this was built into their school day almost as like a vocational opportunity for them. And they became BU employees and were paid hourly, which was really meaningful to the young adults.

[Ariel Schwartz 18:29](#)

So, you know, on one of the big lists of doing PAR is the logistics is figuring out transportation is how are we going to make these logistics happen. And I think that is a big responsibility of the research team. If you want people to show up, that shouldn't be a burden that you place on your partners, in my opinion. So we had to do all that. And so then the way we decided to do it was that they came to BU for two hours a week from September through September through like August, really? And so we came two hours a week we did various tasks around, you know, just introducing them to the topic, well, what is mental health? What does mental health mean to you, and walking through different phases of research leading up to designing the intervention. And then we had a few sessions that were very focused on training to be a mentor and role play. And then they did mentoring the following fall, and they were provided with a lot of one to one support during the whole process of being a peer mentor. And we are going to be kick starting our meetings up again very soon to analyze data from that project.

[Jeff Sheen 19:37](#)

Thank you. That's very helpful. I was curious while you were talking, what what if anything, surprised you about this experience that you maybe thought you had a handle on but then there's a surprise arose or? And then related to that what what kind of maybe unanticipated challenges did you face if any?

[Ariel Schwartz 19:58](#)

I think that, I think it's something really important to think about for me, and I was really surprised so much. It's just something that I really internalized over the course of doing this is the importance of preparation. And when I wasn't prepared, the meetings didn't go well, when I was prepared, it all went well. And thinking about how there were sometimes some little decisions that I struggled with, and they didn't seem like big deals. But then as soon as I brought them to the group, they kind of affirmed it wasn't a big deal, but then they made a decision very easily for me. So learning to rely on them to be my brain was really helpful and kind of took some of the pressure off of me as the PI. And and just reaffirmed over and over again, that using this approach is the right way to go. But of course, yeah, this isn't really answering your question, but there's a lot of nuance there. And like I have the capacity to be working on this project five days a week, and I had they worked with me two hours a week. Right? So 100% was not done in partnership, there were some pieces that I did without them. And that's a big tension in doing this work, and so be really thoughtful about what could be their unique contribution and making sure that I was fully prepared to present it to them. So I don't know the answer to your question at all. But those are some lessons learned.

Jeff Sheen 21:28

Yeah no, you and you talked a little bit about the whole the kind of importance of sharing power. Can you tell us a little bit about how, how did you have those conversations? And how explicit did you kind of make that about sharing power? How implicit was it? How did that kind of how did that work in this project in particular?

Ariel Schwartz 21:48

Yeah, so I tried really hard to just continually remind them that I wasn't in charge, but of course, they saw me as in charge, right. I was coordinating our meetings. I was kind of the one bringing what you're going to do to them. So there are other teams that use a different model where it's a little bit more collaborative and even planning the meetings. And of course, that would be ideal. And that would maybe, perhaps be a pure form of power sharing, but I didn't have the resources or time to do that. So I spent a lot of time just saying, "What do you think? What do you think?", and then acting on what they said. So if they told me to do something, I did it and I hope that over time, they saw that and that would help them speak up more and more.

Ariel Schwartz 22:31

And, and part of it, I think, has to do with just kind of how you present myself, how you present yourself, like I naturally am someone who's never going to be dressed very nicely, but I think it you know, makes a difference that you kind of are if they're wearing jeans, I'm wearing jeans, as opposed to you know, we're all coming together in a group and I'm like in some suit that's automatically a sign of I have a different position than you. So it's things like that. And making sure that we form relationships. And I got to know them as people. We did something at the end of every session that I borrowed from many other people before me, where we did like, what do you want to keep? What do you want to change? And how did I contribute to this meeting? And we did that at the end of every single meeting. And I think that that helped people understand it, this giving input was really, really important and that they were able to then identify their own contribution. And recognize Okay, I did contribute. I did use my power today.

Jeff Sheen 23:33

Yeah, no, I think that's that's a really important perspective to be sharing with our listeners. And I think about similar experiences, right, the whole idea of, I was more than happy to not wear a tie because it set up that different dynamic and so to kind of be in the similar state of dress, as the young adults were. I think the important piece I want to cue on is really how important is to compensate these individuals with lived experience for their everybody else in the room are involved in the project is getting paid. And if you're if you're not compensating the individuals that you're incorporating into inclusive research, is that really inclusive research? Right? There needs to be the compensation and an understanding that they are experts on their experience and you are, you really can't do this work without their expertise. Right? They can probably go happily along with their day without having to spend time with a researcher. They really are the experts that are doing a tremendous service to the field by spending their

time and energy talking about these things from their lived experience and compensating them is absolutely critical.

Jeff Sheen 24:39

Absolutely, yeah. And I ruined my budget that they get paid \$20 an hour and all their transportation will be paid for and that was extremely, extremely important to me. So they got paid more than the graduate assistants working on the project.

Jeff Sheen 24:51

That's that's an interesting tidbit. I think that's that's another thing. So sometimes, sometimes, we do talk about compensation, but it's not fair market value compensation. It's here's \$50 to come spend the day with us and \$20 an hour at a lot of places. That's, that's more than a lot of graduate assistants are making. And I think-

Ariel Schwartz 25:09

Yeah it is across the board more than ours are making

Jeff Sheen 25:11

Right. And that certainly says a very. Yeah, that sounds that sends a powerful message. For sure. I appreciate that. I'm just curious, as you've reflect now on this project that you've done, and you're going to continue to do this work, you're starting up your meetings, like you said, in the near future. What, if anything, are you going to do differently based on this last years of experience?

Ariel Schwartz 25:36

Well, we're moving into a really different phase of the work. Now we're analyzing data and reflecting on how to try to make it better. This group has not done a ton of data analysis. So we've done it. Yeah, I don't know. I don't think I have anything thoughtful to say. That's a good question. So it's a totally new phase. Yeah.

Jeff Sheen 25:59

Will you be working with the same group. Are there new people joining the group? Is this the same group you're gonna be working with?

Ariel Schwartz 26:04

Yeah, it's gonna be the same group. And, yeah, we are gonna be doing a lot of data analysis. And I hope that we had a meeting right after the intervention ended a little we had a party and a kind of a focus group among the mentors to think about what could have been better. And I think that it will be interesting because in some ways, when we analyze the data and see what people are saying about the intervention, instead of them reflecting back "Hey, Ariel, this actually be brought to us is okay, or it sucks or it's great. It's gonna be also reflecting on what they did. And seeing their own role, and I don't know if that's gonna open up a different conversation a more difficult conversation.

Jeff Sheen 26:54

Ariel, it's really been great to talk with you. I'm just curious if you have any other thoughts that you want to share with our listeners that we haven't got to.

Ariel Schwartz 27:01

We didn't talk a ton about mental health for people with intellectual and developmental disabilities. But I think that it's it's great that this area is getting more recognition, it is clearly a need and under studied and under addressed. And so I'm really excited about the the enthusiasm in the field and greater recognition of the fact that you know, societal oppression, it can also impact someone's mental health. And if you are living in a world that is, is so oppressive, that you may have some mental health needs. And so I'm glad that it's getting addressed from all angles.

Jeff Sheen 27:40

Yeah, that's, I appreciate that. And I want to just follow up with one final question. So Arielle, we do like to end our discussions with some kind of action item for our listeners. So when you think about what you would put out into the universe, as far as encourage people to make the world more inclusive, or ways that people can support their own well being or support the well being of others. What would you kind of recommend folks be thinking about this week?

Jeff Sheen 28:05

I think we all we all need community and relationships are so valuable. So if you're not a person with an intellectual and developmental disability, I think forming relationships with folks. And it can be through something you love. I got into this through through soccer, which was something I was passionate about and sharing that passion with someone else and, and meeting people with disabilities who had that passion. So I think anything you can do to find commonalities and build relationships and get to know one another, can help foster a more inclusive world.

Jeff Sheen 28:35

Thank you so much for those heartfelt comments. And thank you for taking the time to visit with us. It's been really delightful to to hear your passion and to hear the work that you're involved with, and I'm really looking forward to meeting the rest of the group and talking to them in a couple weeks. And so, we'll talk to you soon. Thank you so much.

Jeff Sheen 28:53

You're welcome. Yeah, they're super excited.

Alexandra Schiwal 28:56

Once again, thanks for listening to this week's episode of The MHD Crossroads podcast. Remember to follow us on social media at at MHDD center or go to our website which is MHDDcenter.org. Come back for our next episode where we'll talk to some of the young adults with intellectual and developmental disabilities that work with Dr. Ariel Schwartz, who we just heard from. Remember to like, listen, and subscribe to our podcast wherever you get your episodes. Thanks for listening this week. (Music Plays)

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