You First Podcast - Accessibility Outside the Box Episode 6: Research

Maddie Crowley: You're listening to "You First," the Disability Rights Florida podcast. On this episode of our series, "Accessibility Outside the Box," we will talk about accessible research.

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Maddie: Hi there. I'm Maddie, co-host of the You First podcast. Welcome to the final episode of our series, Accessibility Outside the Box. I can't believe we are already at our last episode.

Keith Casebonne: I know. Me neither. Hi, everyone. I'm Keith, the other co-host of the podcast. Thanks to those who have been following the series so far. For those who are listening to this episode first, welcome.

Maddie: Today, we're excited to have Rua Mae Williams on the podcast to talk about accessible research. They are an academic researcher who studies how technology, design, computer research practices, and disability justice interact.

Keith: They touch on a variety of concepts, like how to do accessible and inclusive outreach to potential research participants, how we can offer other data collection options so people can more fully and authentically participate, and how we can see the future of research in a different light.

Maddie: It's a super interesting conversation, and we hope you all enjoy our interview with Rua. Hello, Rua. Thank you so much for being on the podcast. It's great to have you here. Please, introduce yourself, tell us a little bit about you.

Dr. Rua Mae Williams: Hi, I am Dr. Rua Williams. I'm an assistant professor at Purdue University in user experience design, and I do research in the interaction between disabled people and technology development. In particular, I am investigating how all of these things impact disabled people's rights and justice.

Maddie: Wow, that's interesting. There's so many fields of disability studies as it connects to other fields of practice and academic fields of study. I haven't been super familiar with what you focus on. It's super great to have you on the podcast and be able to talk a little bit more about that.

When did you start doing research? I know you said you're at Purdue now. What kind of experience have you had, and what kind of barriers have you faced along the way?

Rua: I probably didn't start doing research until I started my PhD program, which is a little bit unusual for many PhD students. They often have done research as undergrads or in master's program.

I had worked in industry for a long time in video games and also in other kinds of tech startups. I got tired of the way those industries run themselves. I went to academia, which is also not a great place, but I choose this one.

[laughter]

Rua: I started my PhD with not a whole lot of a solid idea of what I wanted to do, just that it was human-centered computing and I was going to figure it out.

It was an intentionally interdisciplinary program, but I found that when I came to them and told them, "I want to do disability studies and human-computer interaction," they were like, "What? No, not like that."

Maddie: [laughs]

Rua: When they were imagining interdisciplinary, they were not imagining humanities integration, but they let me do it anyway. I got away with it, and I got a degree. In my research, I was doing a lot of research of researchers, which is where my primary focus is.

I'm doing investigations into the motivations of researchers in the practices that they do, and how sometimes, the implicit assumptions that researchers make and some of the norms and research practice do harm, and specifically harm to marginalized people and disabled people.

Maddie: Tell us a little bit more about some of the recent research that you've done as it relates to what you just mentioned as far as inaccessibility and lack of structure when it comes to designing accessible research and assessing the implicit biases that researchers might have against marginalized folks, disabled folks, BIPOC folks.

Rua: One of the first things that I noticed is I was doing an extensive literature review, where I was pulling all of the literature I could find on a specific topic. In this case, it was technological interventions in human-computer interaction for autism.

In reading these papers, it became clear to me very quickly that as part of making their work seem important and urgent, many researchers will say very unkind things. It's not that they want to be mean or anything. It's part of the way academia makes you market your work.

They're relying on normative narratives of disability as tragedy in order to do that. Not only are they speaking about autism and autistic people in this very negative way, but they're also building the research projects on this fundamental assumption that disability and autism is something that must be fixed and cured.

That the good outcome for someone is that they're indistinguishable, that you can't tell that they're disabled. Is what disabled people want. They want to be invisible or to be "normal." What I knew from my own participation in disabled community and reading by disabled authors is that that is not what disabled people want.

I was curious about why there was this huge disconnect. One of the things that I noticed that stood out to me was how many people would claim that they were using participatory method in their research. Yet, they were still getting these same outcomes, where the technology was designed to fix.

Maddie: Sorry to interrupt. What does participatory methods mean, for folks that might not know?

Rua: Participatory method is a longer tradition of the research methodology, which is supposed to involve human participants in the shaping of research inquiry, and method, and outcome.

What I found is, especially in the autistic technology sphere, you would have somebody say that they were using participatory method, but the participants they meant were therapists, or teachers, or sometimes parents. Either way, the participation that they meant was after inquiry had already been instead.

They've already designed a research project, and then they bring in participants to shape the technology design, but when you've already locked in this frame of fixing, which was never the intention of participatory method. Then, I began exploring, "Why is this? Why are we doing this?"

What I found was that people were claiming, I don't mean to say claiming as if they're lying, but what they're coming up against is that if they want to do truly participatory method with disabled people, the ethics review board have problems with that, because they have conceits and assumptions about disabled people's capacity.

There's this huge systemic ecosystem of doubt about the capacity of disabled people that leads to this kind of research that is fundamentally at odds with disabled people's desires.

One of the things that I explore is ways to make participatory method accessible to a population of people that ethics review boards fundamentally believe cannot participate. It has been fun. That is sarcasm.

Maddie: [laughs] You talk a little bit about how to make people with disabilities, disabled folks in the community more involved in that preliminary process, the one true end-all be-all way to shape research to be accessible.

Are there other better ways or additional ways that researchers can acknowledge and represent disabled voices in their studies, in the frame and framework and building of studies, things like that?

Rua: What I find a lot when I speak to other researchers is there's this strong desire for, "Give me a method. Give me a framework. Give me bulleted lists of things to do, and when I've checked off all the boxes, I've done the thing right."

The real problem with all of this is where all of these disconnect come from is a lack of authentic relationships between researchers and the communities they intend to "serve." There are many different complications to this, and one of which is we do have a number of researchers who are within the communities that people are trying to research.

At the same time, like for myself, I am an autistic person and otherwise disabled, but I also have an immense amount of privilege over people who I would be considering my constituents or participants, because I have a job, [laughs] which like 86 percent of us don't have.

I have a degree, and I am mostly speaking most of the time, and I'm white. These are things that give me power over my participants. When we have researchers that claim to be within the community, sometimes they tend to forget how much power they still have over that community.

Maddie: You talk a little bit about the power dynamics and the ways in which access to academia, employment, different power dynamics that function as identities of race, disability, gender, things like that, and how that affects people with disabilities and disabled folks from being involved in research.

It makes me think about how a lot of research probably doesn't necessarily, those aspects of power in their design, in their own personal identity as they go about their studies. I know at the end of research papers, there's always a limitations section, typically, but more often than not, folks that do research don't often name these things.

They name that they might know somebody in the community, or they have a limitation, whatever it may be, but sometimes they don't necessarily engage, and question, and challenge their own identities and access and how that limits them to be able to thoroughly and authentically perform research that's going to be beneficial to folks.

Could you maybe talk a little bit more about what your experience has been with that and how you've been able to maybe remedy that and perform research in an authentic way?

Rua: I would say one of the primary barriers to accessibility in the research space has little to do with what we consider accessibility, in terms of accommodations, or communication, modality, access.

That's the disconnect between what researchers are prioritizing and the actual immediate material needs of the community. [laughs] An example I can give is that Purdue has a autism research center, and they recently had a conference this spring.

Every single speaker that they had at this conference was talking about etiology and detection, so finding the cause of or possible correlations to autism, and how to then have earlier and earlier prediction. If you ask me as a person, I don't think we should be doing that research at all.

To be more pragmatic, it's just that, why is it the only thing? When you ask autistic people, children, and adults, whatever, they don't need any of that prediction or detection. They're already here, and what they don't have is a meaningful inclusion in work.

I don't mean to say that a job is fundamentally essential to being a fully realized human being, but a pursuit of some kind of fulfilling nature. They don't have adequate access to healthcare. They don't have adequate access to housing and food.

These are the things that people are dealing with on a day-to-day basis, but all of the research money is going to detection. Honestly, it's a bit frightening, because what that detection will ultimately result in is the eugenic erasure of autistic people, which is uncomfy.

That's where we have a primary accessibility barrier in research is that people are not researching things that the participants are interested in.

Maddie: There's a clear disconnect with what folks maybe, not to make assumptions, but nondisabled, maybe non-autistic folks in research, their interests lie, or where they feel that the priorities lie that aren't in connection to what people in the community actually need and what their necessities are on a day-to-day basis.

How can researchers that are maybe trying to move towards that framework, trying to be better in reaching their communities and be more mindful about how their research is impacting those communities, how can researchers move towards what you're talking about and being more intentional and mindful of what the community needs?

Rua: One of the pushbacks I get from researchers is, "That's not where the funding is." One of the first things that we as researchers have to do is to contact the funding direction, and that's easier for some of us than others, obviously.

If you want to have an authentic connection to the community, you have to start with what the community needs, and they will tell you. If that doesn't align with funding sources, then you have to be clever and strategic about it.

Also, researchers like to pretend like it's out of their hands, but we wind up on NSF boards. There is a path from researcher to influencing what gets funded. That's the kind of allyship that we need is people changing funding direction.

These kinds of things and the strategies that we use to transform research have to happen at every level. People like to consider themselves this closed ecosystem and not think about, "No. Actually, we can make broadscale changes with our human relationships that we have with other people, but it comes at all levels."

Policy, funding, the research inquiry that's done, participatory methods. People have to find the area that they can make the most change in, and that nobody is going to do it all by themselves, but nobody has to. We can all do this together.

That's one of the things that I find people stare at me like, "What are you talking about?" I'm like, "I'm the one that's clinically incapable of making friends, apparently, but you're acting like you don't know how friends work. I'm so confused."

[laughter]

Rua: It's like that. I don't know.

Maddie: That makes a whole lot of sense. To some folks, that might seem daunting. Those choices and those steps to make research more accessible, and approachable, and inclusive for folks, it takes work. It's a system that wasn't created to be easy to do this.

To go back to mention something that you said as far as these broad, not necessarily broad but these bigger goals of making research more accessible and important to what the community needs is obviously incredibly important. Also, I know a lot of researchers might not even be familiar with how to make their research accessible.

Whether that's through redesigning research materials, whether that's readings, or creating a space that's more if they're doing an interview, like a research interview for the participant. Making that space that they're doing the interview in more accessible, more comfortable for the participant, things like that.

Could you talk a little bit about how people can make their research practices more accessible and inclusive for folks if they're not able to reach these goals of redirecting research as a whole to be more inclusive to the community, but what smaller steps they can take to ensure that their research is accessible to folks?

Rua: Absolutely. As far as accessibility within the lab, so to speak, goes, this is another place where researchers will often come up against ethics review as a barrier to doing ethical research.

For example, the way that we do consent procedures is fundamentally inaccessible. It's a very legalese document. Even though in the document, they tell you to write in plain language or middle school reading level, the whole format of it, it's very daunting and aversive.

It can be difficult to get your ethics review board to approve a consent procedure that looks more like a comic book, or other forms of plain language or easy-read materials, which is very funny, because then, this turns on and the researcher will say, "We interviewed parents because ethics review would not allow us to interview children or people under guardianship."

It's like we have to get better at communicating with our ethics review because it's honestly that they don't know, and they will change their minds if you talk to them. These are the kinds of things that we have to work towards, and you have to be unsatisfied with compromising your ethics in order to get through ethics review.

Consent procedures is a place where we have the very first barrier to participating in a research protocol. Some ethics review are very antsy around the idea of using text-based interviews, because they are worried about things like data privacy and leakage.

There are ways to get a secure text-based communication between two people, but you have to investigate it and substantiate it and explain it to your ethics review board.

In the case of autistic and many other disabled people, or anybody who has affected speech or people that are deaf, and you don't have the finances for interpreters or whatever, there's many different ways that a text-based interview is more effective.

In my particular population, autistic adults, the way that it can be asynchronous and that they can send me floods of texts [laughs] and not be embarrassed by it, and they can say, "I'm not done yet," and I say, "Go ahead, keep going," these are things that make the data that you get much more meaningful than if you made somebody come and sit in a room with you for an hour.

That is not the means by which that population is most effective at communicating. The data is more valid when you do it in this other way. Another thing that I talk about that's a little bit less in the qualitative sphere is many of the methods that people use for observation in the lab, they will look at only audio, or only video.

There are some papers that show that when you only look at one mode, you're missing the multimodality of communication that is most common in people that don't have equal access to oral language. You will make assumptions about somebody that are wrong without both channels of information.

Those are the kinds of things that I talk about, like how can you make multimodal expression a core part of your research protocol? In particular, how can you integrate ways of being attentive to what we call in disability studies crip time, which is disabled relationships to time are different and often not best expressed in these one-hour lab visit chunks?

How can you give people more time to process and to give you the information that is valid?

Maddie: Those are all good examples. I think folks listening, researchers listening, PIs, whoever it may be, that hopefully can benefit from some of the knowledge that you're sharing will take some of this away hopefully and truly understand how to make and approach research in a different way to be, like you said, even more valid research or more accurate research.

It's not necessarily encompassing the whole individual when we don't do multimodal review of the participants' engagement.

For researchers that are listening, and for folks that are already involved in research, a lot of students maybe in academia, how can folks involved in research make their spaces, whether they have physical spaces, virtual spaces that they communicate about their research, different whatever their practices may be for communication, how can they make those more accessible for disabled students and scholars in academia?

Rua: There's a few things. First of all, sometimes, your lab isn't the best place to do the research and think about ways that you can come to the community where our space is, where people are comfortable, and that you can come to invite in.

Also, for all kinds of different disabilities, there are many ways that campuses are completely inaccessible. There's also ways that campuses are inaccessible to people who are relying on public transportation, or who do not have access to parking. There are very many ways that making people come to you in a lab is not the way.

In the space that you have, you should be attentive to somebody's physical comfort, and that includes the well-known sensory domain of the lighting and the sound. Some people and some engineers work in buildings where there's literally ballistics happening in the basement.

[laughs] Please don't make somebody go to your...It's not your fault that you share a building with the ballistics researchers, but you're going to have to go somewhere else.

Maddie: Oh my goodness.

Rua: [laughs] In these kinds of things, it's being attentive to where you're bringing somebody and how they may feel like they belong in that space.

Again, I like to get people to be more realistic about what you can achieve in an hour if you're going to confine your sessions to an hour and be more thoughtful about how you can open up the space for communication and collaboration beyond that hour.

Even if you're doing something on a routine basis, where you're coming in multiple times a session, the processing that happens about what is occurring to you in a lab setting over that hour, some people aren't going to be able to tell you how they experienced that hour until a week later.

Think about how you can be attentive to giving the person space and time to process. If you're looking for valid and engaging qualitative data, you need to be thinking about very unstandard or unique ways of collecting this information.

Maddie: Thank you so much, Rua. One last question, if you could give advice to yourself four or five years ago, maybe young disabled scholars that want to get involved in research, what kind of advice or thoughts would you share with them as they go into this space?

Rua: Do not assume that your own experiences are good enough as a frame for beginning inquiry. You're one person, and if you really want to make changes in the community, you have to continue to be attentive and reflective, and having authentic relationships with multiple people from within that community.

Also, people will doubt you. They will doubt your capacity for the work. They will doubt your motivations for the work, because you will be contesting dominant paradigms and they don't like it. All I have to say about that is to keep firm about it.

You have also predecessors and elders, if you will, in the space that you can look to that you can use as strategizing and bargaining chips, so to speak, in validating your work. People that are "the hegemony" will be resistant to the change that you want to bring because it undermines their careers.

What I get frustrated with, and we can all work together on this, is there's no reason why an established tenured researcher can't change direction.

I feel like researchers that are resistant to these kinds of changes need to stop and reflect and think about, "Isn't it a wonderful opportunity to go research new directions? This is actually good, and exciting, and not scary." Yet, this is how people react to it.

What I try to do is I try to get people to see the hope and the potential behind these transformative directions. This is not about ending your career. It's about a new stage. Hopefully, with that kind of frame, we can all move forward together.

Maddie: Wonderful. Rua, thank you so much for being on our podcast today. It was wonderful to listen to what you had to share. I hope listeners get to implement some of the things you share and grow in themselves as well. Thank you so much.

Rua: Thank you very much for having me. It was fun to be here with you today.

Keith: Thank you, Rua, for being our guest on this episode of Accessibility Outside the Box. We hope you all took something away from this episode like Maddie and I did.

Maddie: Definitely. We are so happy you all enjoyed the series, Accessibility Outside the Box. Did you miss an episode? Don't worry, we're on all podcast platforms, Apple Podcast, Spotify, Google, Amazon, YouTube, and more. You can find any of those podcasts and also find us on our website at disabilityrightsflorida.org/podcast.

Keith: We are very happy to announce that we'll be back in August with a new series called Voting with a Disability. Make sure to subscribe to be alerted when it drops. Thanks again for listening to the You First podcast or reading the transcript online. Please email any feedback, questions, or ideas about the show to podcast@disabilityrightsflorida.org.

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