UIC Participatory Action Research (PAR) Podcast Series
Reflections on Leadership, Authenticity, and Self-Acceptance in Participatory Research

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Announcer: Welcome to the University of Illinois at Chicago Center's podcast series on Participatory Action Research, also known as PAR. This methodological approach involves researchers working collaboratively with people whose lives are affected by the topic being studied. Together, they choose the research questions, decide how to gather and analyze data, and disseminate the results to a wide variety of audiences. Our series features people with lived experience of mental health conditions sharing strategies that promote inclusion in all stages of inquiry. Join us to learn more about the value and impact of PAR on translating evidence into action.

Jessica: I'm so pleased to be joined today by Dr. Laysha Ostrow, who will reflect on her journey to becoming a successful mental health services researcher, along with the barriers and challenges she overcame along the way.

Welcome, Laysha! I want to start by talking about how you decided to pursue a career in this field. I understand that you had a very difficult time in high school. And once you made it to college, you started out as an English major, but then switched to Psychology. Can you talk about why you switched majors, and how these experiences led you to pursue a career as a mental health services researcher?

Laysha: Sure, thank you so much for having me here today, Jessica. I'm really excited to talk about this topic. When I was five or six, I always said I wanted to be a writer when I grew up. I even put this in my first grade journal, which I still have in my closet. But by the time I went to college, I had been living in a special education facility for emotionally disturbed teen girls for about three years. In my last year there, the state of Massachusetts declared me mentally incompetent, and I had a court-ordered antipsychotics and got on SSDI.

About a year later, I went to college. I hadn't at that point been in a regular classroom in almost four years. I hadn't been in a multi-gender environment either. I had lived in a very controlled way and college was completely overwhelming for me.

I liked my English classes, but everything seemed abstract and theoretical. In my psychology classes, I understood what the professor was trying to teach before they'd even assigned the homework. I had read the whole DSM when I was locked up, along with books on research studies in psychology, because that's what I had access to during my high school years. When everyone else in class was wondering what disorders they might have, and you know, the things that go on in intro level psychology classes, I already knew that the diagnoses are circumstantial and they're not going to fix your problems. Psychology was intuitive to me in a way that other subjects weren't.

Jessica: Yeah, you had lived through what you went on to learn in your classes. So, you switched to Psychology, but then, everything didn't go smoothly from there, did it?

Laysha: No, not really. I guess I would say looking back that I didn't get the point of traditional schooling. I don't know if that's because I was out of that system for so long at such a young age. But I had the psychology major, pretty decent grades, and a good group of friends at college, but school just

didn't feel meaningful to me, not in the way I thought it should. I had a drinking problem and plenty of lingering mental health problems even though I was in treatment. So eventually I dropped out. I was unemployed and on disability for a couple years, and during that time I realized that I wanted to be a researcher to help other people avoid the problems that I had.

Jessica: As you were talking, I was considering how someone might think at this point – you dropped out of college, you're on disability – seems like becoming a researcher is a pretty insurmountable goal. But, what happened then?

Laysha: I realized it was sort of an insurmountable goal at that point. And I wasn't brilliant or special, and there were lots of stories then, as now, about people who had made it after dropping out of college. But for me, I realized I needed a college degree to do the work I really cared about. I was able to go back to school through a program at Lesley University. The program was structured so you could design your own classes and not be in a classroom with a teacher. And when I was able to do that, I could investigate the things I was interested in – feminism, and creative writing, and maybe most importantly for my career, mental health from the perspective of policy and history, which is what really interests me. And that's not typically taught in traditional undergraduate programs. It's not part of a psychology major to learn about the system that these services or problems exist in. Then when I finished my undergraduate degree, I wanted to get a job in mental health policy research, and coincidentally, I lived around the corner from Human Services Research Institute (HSRI), which is a research consulting firm in Cambridge. It took a little persuading, mostly because of funding I think, but they were willing to hire me as a Research Assistant.

Jessica: That's fascinating, and I'm guessing many of our listeners can relate to a non-traditional path. Can you talk now about how the work you did early on informed your own path? Is that how you got involved in the community?

Laysha: It is and it isn't. At HSRI I worked with a lot of the people that became really important to me, and researchers who have done groundbreaking work in this field. Some of them became mentors to me, like Judith Cook, Ron Manderscheid, Mark Salzer, and Neal Adams.

But HSRI also worked with people with lived experience on their projects. Judi Chamberlin, who maybe a lot the listeners know – she wrote *On Our Own* -- was on the board of HSRI before she passed. So, with the culture there, it wasn't weird for me to work there as a researcher, and also be open about my lived experience. They even gave me Judi's book on my first day of work. I had never really read anything like that. Steve Leff -- who was running HSRI then and started it -- I asked him one day about the advocacy community, what's their role, what's the importance, why do we involve these people in our projects? And he said that, if it wasn't for people like Judi and their advocacy, I'd still be living in an institution. That kind of took my breath away for a second! I wanted to debate it with him, but I realized he was probably right.

But there was also a disconnect, the way I saw it, I had this sort of natural inclination to push back on that because I thought research and policy are really important, and wondered what is "the movement" as they call it. And a lot of those people do very high-level policy work, but they're not scientists necessarily. I didn't want to be an advocate. I didn't want to be put in that pigeonhole that, because I'm working in a field where I also have lived experience, the only thing I have to offer is my lived experience. I wanted to be a scientist. And part of that is the change I want to do in the world, but also because personally I feel my best when I'm intellectually engaged. If I'm not writing or reading or crunching numbers, I'm probably falling apart. That's kind of what keeps me going every day, whether in a work context or

personally. Looking back, being out of school in my teens and twenties and in chaotic environments where I couldn't concentrate was the worst thing that could happen to someone like me.

I worked with a lot of people with lived experience who were consumer advocates and advised on projects at HSRI, but it wasn't until I was in my Master's program that I started working with those people on my own. I wrote a paper for school on peer respite programs because I was interested in the claims around cost-effectiveness that advocates were making, and I wanted to write about how you might study that question. And then, I handed it off to the community, and it got sent to SAMHSA, and people really liked the paper and thought it was an interesting problem. What I realized is that different stakeholders see policy problems in different ways, and there's a lot to learn from different perspectives. I felt that, given my interests, I could help make sure that voices that aren't often "published" have their vote, using data.

Jessica: That kind of insight is fundamental when figuring out what career path will bring satisfaction, and even joy. Which then leads me to ask, what do you enjoy about doing this research?

Laysha: The thing I enjoy most about it is that I can put my labor where my values are. There are a lot of problems the world is facing, and I can't personally stop climate change, or forced treatment, or poor working conditions for everyone. But I can do the little bit that I can do to make the world a slightly better place, at least. I couldn't be happy if I wasn't doing that.

The other important thing when talking about joy is that I get to write, and talk to smart interesting people, and think about how to solve hard problems and come up with new ideas. Right now, my work is focused on self-employment and fair employment practices, and it's a really good time to be doing that work because there is a growing collective consciousness in the political and economic systems about working conditions because of technology and the pandemic. People are trying to find new ways to work, and workers have more power than they've had in a hundred years. I am excited to be a part of societal change on that scale, and to help make sure that people who are differently abled aren't left out of the benefits of that kind of social change.

Jessica: I've been finding that inspirational too! I agree that we're at a tipping point around more widespread acceptance of the value of universal design for all workers. How can we make work better for all of us?

I'm curious what you consider to be some of the pitfalls of this kind of research? In particular, I understand you've had some conflicts doing specific projects, as we all have. So, I wonder if you could talk about how those came about, and what you'd want other people to know about resolving conflict, especially when doing participatory work?

Laysha: I think one of the points you just made is probably the most important thing, is to realize that everybody has these conflicts. So often, for people with lived experience, when we have negative experiences in the "normal world," like at work, we think that this is because of me, and everything they said about me is right. Or, it's because I'm working with other people with lived experience that we have these problems. But everybody has these kinds of conflicts. Normalizing that is important.

There was a point at which my ambition and my credentials started to align, and that's where I got into trouble. It was the years around when I finished grad school and it was time to go out into the world and actually do something with all this education. I had tools I needed like training in research. But I also didn't have other tools that I needed, because in graduate school, they don't teach you about what kind of

worker to be, or how to manage your time, or how to manage your relationships. They don't even really teach you, at least not where I was in school, how to decide what you want to do next.

I felt like I finished, and then, theoretically, there were a lot of options. I ended up starting Live & Learn and working for myself. Then the biggest conflict in my career so far, hopefully ever, that I ran into was a project when I was first starting my business after graduate school. It was a project on the experience of stopping psychiatric medications after long-term exposure. At that point, I had been a student and I had research assistants working for me on my dissertation, but I really didn't have a lot of experience managing other people. And, because I was self-employed, there were additional challenges operating outside an institution. If I was at a university there would have been support for things like contracted labor, which is where I ran into trouble. There were a lot of people involved in the project, and most of them didn't have any professional training in research, which is what you see a lot on participatory action research projects. A lot fell on me that I wasn't prepared to deal with, including conflicts around scientific methods. I understood the methods, but I didn't necessarily understand how to get buy-in from stakeholders about that, or explain things, or work out those kinds of conflicts. And we were working outside the system, so things got out of hand rapidly and I couldn't manage it.

So, I thought a lot about that experience, and the most important lesson I learned was that if I'm the project director, or PI, on a project, I need to assert myself as an authority figure. And one of the things that makes that most difficult is that in the peer support world, where I've worked most of my career, we talk a lot about the harms of power dynamics and authority dynamics between "peers." But I had to change my mindset, and think, working as a peer supporter is different than working in research as a person with lived experience. And, going back to normalizing, if you read about project management and leadership, you learn that authority doesn't have to be harmful. Authority can also refer to having knowledge and expertise. Different stakeholders on projects have different forms of authority. Mine happens to be that I know about research methodology, and I'm the person leading the project. So, I think there's more harm to be done by pretending you don't have power, than in being transparent about the kind of power that you have.

Now when I run projects, I always make it clear to the people working with me what the decision-making process is. As the PI, you're going to decide what the decision-making structure is, or deciding as a group what is the decision-making structure, whichever way you want to do it. For me, I still am a person with lived experience, so I can be easily triggered, I have a lot of stuff going on in that way, where I have to be conscious of that and transparent about it.

So, if you can be comfortable with the kind of power you have, then solid leadership can create more trust. It doesn't have to be authoritarian. I've had to get comfortable with the fact that, if I'm named as the PI, then 'the buck stops here' in terms of accountability to our funders and the public, in terms of making sure the project gets done, and is done well. So, it's important to me to be clear that I make the final decision on these projects, but also while soliciting input and collaboration from the people working with me. Since I started working that way, I haven't had power struggles on my projects.

Another challenge I wanted to talk about is being spread too thin when it comes to involving community stakeholders. When assembling a team, I want to have as many perspectives represented as possible because it improves the design of projects, and helps with tasks like recruitment, but then you run into issues with management and compensation. For instance, the kind of NIDILRR grants I have worked on have not kept up with inflation or cost of living. And that's not because of NIDILRR, that's coming from above them, and a lot of agencies and researchers are facing this. So, every year we're doing the same (or more) with less. I am grateful to have my work funded by the federal government, even though I'm in a

nontraditional research setting, which to me felt like an insurmountable challenge at first, and it's been so beneficial. But, it really becomes a problem when you believe in compensating people – especially people with lived experience who are often asked to volunteer on projects and its implicit that there's not even a way to ask to be compensated. I get people trying to have me work on their projects where there's not even a mention of a contract or compensation. But people need to be paid for their time, because they have real-world experiences. We need to figure out how to have adequate representation, and shared power on a project, when you can't really even pay people for their time because costs are continually going up while grant amounts are not going up.

Jessica: We've experienced the same and it's a big challenge.

Laysha: I know. I think it's a challenge for all researchers or anybody who is grant-funded. But with participatory action research, you're basically divvying up a small amount of money into tiny, tiny pots to give to people, which isn't really enough to get their investment. And rightfully so. It's not on people to invest in things without compensation. They have mortgages to pay, they have children to raise.

Jessica: The nice thing is that they're becoming more empowered, so they're able to say no, I deserve more than that. I'm worth more than that.

Laysha: I think you make a really good point about how to get that word to the people who actually make these decisions. I haven't sent them yet, but I have a letter written to my Congress people about this specific issue. Speaking of my personal experience, how am I supposed to run these projects?

Jessica: I agree! So, going back just a little bit, I wonder if you can talk more about how you go about building trust with community members and teams? We know that can be difficult when we don't have enough money to compensate them, but I know there are other ways we can build trust and engagement with people.

Laysha: Looking back, I got some push back when I first started going to meetings or being on email lists with people who were doing community organizing (that's how we did things before social media and Zoom). People would accuse me of being a Pharma shill, essentially a traitor because I decided to become a researcher instead of mostly relying on my lived experience. So, I often didn't announce my personal experiences when I met people. I might nominally say something, but I wouldn't get into the details of it. It's one of my qualifications for doing this work, but before I understood how to harness that, I didn't claim it. Part of what got me through those initial hazing rituals was that my early life in a mentally ill family, and living in institutions and all of that, I think I feel more at ease than a lot of people feeling like I don't belong, and people not trusting or liking me is not going to stop me from doing what I think is right.

My advice to other researchers who want to involve the community is to put yourself out there. You have to let people get to know you and get to know them, and that takes time. Find groups that share your interests, and ideally share some of your ethics. Like seeing community groups, advocates, and the people you're working with as colleagues is really important. They might have a different skill set or interests than you do as a researcher, but that's why we're there: to do co-learning. That's why long-term relationships are so important. There has to be time and space to learn and grow together. Aside from the compensation issue is focusing on the relationships when you can.

Jessica: Yes, we talk about that, too. It takes a lot of time and transparency, as you've talked about. Naming things upfront and being transparent is part of building those relationships.

Laysha: Yes, any relationships, right? The same principles apply to all kinds of relationships! Be honest, be fair, be kind! And put in the time.

Jessica: Another problem, of course, with grant-funded projects is we don't always have that kind of time. But your point is certainly well-taken.

Laysha: That's one of the issues I see with people trying to get into participatory action research. They're doing it around a grant, whether that's while they're writing it or when starting it, and you really don't have the time. There's so much pressure at that point. You have to go out of your way to invest in those relationships before you start the project. And hopefully, you build steady relationships. At this point, I have people I work with a lot on different projects. We have that history and trust.

Jessica: For emerging researchers, knowing that it's going to take time, but you can build those relationships over several grants or projects.

Laysha: Graduate school is a great time to do that because, even though you think you have no time, you're going to have even less time in your 40s!

Jessica: That is so true! Sort of related, you know I've been in the field for a relatively long time now. One thing I always like to ask – even for my own learning -- is how you personally maintain energy for research, and particularly, participatory research over the long-haul?

Laysha: It's not easy, so acknowledging that, and knowing that some projects and teams are conducive to participatory action research, and some are not. That's something that I've struggled with even recently. Like the Certified Peer Specialist Career Outcomes Study, we're just wrapping up now. That's one of the first projects I've ever done that was not participatory research. That made me very nervous at first. But it was my first longitudinal study and there were so many other elements of that project that were important to do well that I accepted that it wasn't possible to also have substantial community input. With the resources that I had, including my health and my time and the money, it just wasn't going to be possible. I still got input from community members outside the research field on things like the survey measures and recruitment to make sure they would work for participants, but for the most part it was not that kind of project.

The other part is running Live & Learn, which is an advantage I have over perhaps being in an academic institution, is that I decide who we hire. And everyone who works for Live & Learn are people with lived experience, so there's always an element of "representation." That project has been very successful, there's been a lot of interest in the findings from the government and the peer support community, and they are very relevant for improving the working conditions of peer specialists, so that taught me that I can be flexible in designing project methodology for the specific project, and also acknowledge my own limitations in terms of my energy.

I guess that's the lesson in doing participatory action research is that you have to attend to your own energy. I have a bottom line for the work I do: if it makes me sick emotionally or physically then it's not worth doing. There are other ways to earn a living without me having to be sick about it. Hopefully! I haven't tried, but that's what I tell myself! Knowing that you can't do everything perfectly, thinking about the options you do have, and thinking outside the box, even if you don't see things immediately, that helps me keep up my energy for things I do want to do.

Going back to what we were talking about before, having healthy relationships at work that feel rejuvenating is essential. I love having a large group of stakeholders on a project where we are working towards a common goal, and everybody is focused. And part of that is me being a solid leader to make

sure to facilitate that focus. Working in those kinds of groups, where we can be in a flow state around the work, helps me feel motivated and feel connected to a deeper purpose, and that keeps up my energy.

Jessica: Yes, I think communities of belonging are so essential to our well-being. It's true that when we're driven and passionate about things, we can sometimes neglect taking care of ourselves and taking care of others. So, I think that's really good advice.

Switching gears just a bit, can you talk about why you decided to start a business, rather than pursue a career in academia?

Laysha: When I got into this field and went to graduate school, I had no intention of working for myself. If you had asked me back then, I probably would have said that starting a business would be a sign of failure. With everything that I went through, and just our culture, I was desperate for other people's approval, especially the approval from the types of large institutions that had essentially ruined the first part of my life. The only lens through which I saw success was being a big-name researcher in a big-name institution, with them endorsing me.

So, I had to change my perspective on that. If I worked in academia now, I would probably still be taking psych drugs because of the demands on your production schedule – how many papers you have to publish, the grants you have to bring in; and it's not just the number, but is it the right journals, is it the right funding agency, do you have the right people working on it – the bureaucracy of academia dictates the way you do your work. Which is their right because you're employed by them. Owning my labor and realizing that the only thing that really matters is that I love myself and have my own approval, that's really the key to my recovery. That's why I love talking about business and working on research on business because, it sounds so cut-and-dried or capitalistic, but I think you can find yourself in owning a business because of everything you have to confront. All the other accolades I might have earned, if I had tenure, are fleeting and conditional in a way that loving yourself is not.

Jessica: It's such an important thing, this idea of self-acceptance and self-love! It's certainly not talked about very much when we're going through school, learning how to be researchers and adults. I love that.

As we come to the end of our session, I'm wondering if you could speak to how your multiple perspectives as scholar, business owner, and peer make your research unique and innovative?

Laysha: Looking back, every major research project that I've done has been in some sense "me-search." My dissertation was a study of peer-run nonprofits, and in the middle of that I started a peer-run nonprofit. I had already designed the survey and collected the data by the time that started, but when my non-profit fell apart, I realized a lot of my hypotheses about why nonprofits -- and peer-run nonprofits -- fail were wrong. They were based on the literature and what I understood as an outsider to that world, but it could have been a better project if I understood the subject as well as I did after having that experience.

So, my next project was the medication discontinuation one. And, as I talked about, we had some interpersonal challenges on that team, but I think in a lot of ways it was better methodologically because I was actually coming off of psych drugs after 20 years when we did it. And maybe even some of the reasons I felt so passionately about doing the methodology the way we did, and fought for it and had these challenges, was because I understood the subject matter so well at that point.

Now we're doing the Reclaiming Employment project, which is about self-employment, and I feel a very deep emotional commitment to research on entrepreneurship to help people avoid some of the problems that I've had and still have in business. Sometimes, it feels pointless being a researcher when the world is burning down around us and we're at our computers. And I think what I'm doing now is going to take

five years to develop, and another five years to disseminate, and is anyone is even paying attention to anything I'm doing? But then I realize that I have survived and thrived, and that creating knowledge and sharing knowledge are two sides of the same equation, and I have a moral imperative to use that knowledge to help my peers.

Jessica: That's an important perspective because it's easy to feel hopeless in a world of chaos and pain. But that doesn't take away from the importance of creating and sharing knowledge to ease the journey for others.

I want to thank you again for joining me today. I've really enjoyed our discussion, and hearing your unique and valuable insights, centered in your lived experience. Thank you so much!

Laysha: Thanks for having me!

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