

UIC Participatory Action Research (PAR) Podcast Series
PAR in Action: Peer Navigators for the Health and Wellness of People with Psychiatric Disabilities, DHHS, ACL, #DPHF20000135

Presenters: Patrick Corrigan and Paul Williams
Moderator: Kelsi Urrutia

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.

Kelsi: Thanks for joining our PAR podcast series. Today, we will be discussing the roles that people with lived experience of mental health conditions play in a unique study of peer health navigation services in a large community mental health program in Chicago. I'm joined by Dr. Patrick Corrigan, a well-known and highly respected mental health services researcher, who is a Distinguished Professor of Psychology at the Illinois Institute of Technology. Also with me is Paul Williams, a Research Assistant with lived experience working in Dr. Corrigan's Chicago Health Disparities Center at the Illinois Institute of Technology.

Kelsi: Let's get started! Pat, would you give us an overview of the peer health navigator study we'll be discussing today, and how it uses the PAR approach?

Pat: Well Kelsi, people with serious mental illness unfortunately get sick and die 10 to 20 years younger than other people. Part of that might represent their difficulty in managing behaviors that would serve them well, but a lot of that represents health inequities that reflect trying to have one's health needs met in a fragmented healthcare system.

So, think about the challenges of managing your health in Chicago. If you get a respiratory problem, you have to go to the county hospital on the West side. Then, up to the north side to see the podiatrist. Then downtown to get your meds, and then back up to the north side see your psychiatrist. And peer health navigators – well health navigators – are people whose job is literally the walk the individual around the healthcare system, should the individual want it. So, health navigators would be somebody that would help the person get an appointment to the county hospital and then take them to the appointment at the county hospital, and wait with them in the waiting room, and if the person wanted going to see the doctor. And then get on the L and go to the North Shore to see the podiatrist and then come back downtown. So, it's a very practical efforts to walk people around the healthcare system.

Peer health navigators are people with lived experience, people who have experienced recovery of serious mental illness and who, by the way, also might share things like ethnicity, being of

color, or neighborhood - living in the same neighborhood. Peer health navigators are hiring peers to provide this health navigator service.

So, what does PAR offer to it? Well, to be honest, we really need people from the lived community, people like Paul, who can tell us what it's really like to try and get around a place like Chicago to meet all these different kinds of needs given the kinds of pressures and challenges of living in the city. So that's why we put together a PAR team like Paul and an other eight people who are joining us on this kind of effort.

Kelsi: Thanks, Pat. Paul, how did you come to be involved with this study?

Paul: Well, I've worked at IIT for 7 years on different studies. One of them was on health and weight management among African Americans with lived experience of mental health issues. So, working on the peer health navigator study was only a natural fit for me.

Kelsi: Thank you. Paul, would you describe some of your participatory duties on this study?

Paul: Sometimes it's being on job interviews for the team hiring the health navigators. Assessing on how well and open and comfortable they are with sharing their thoughts and experiences. Assessing how they build rapport. And how much they knew about Chicago and the transportation system.

Also, training the peer health navigators and developing the interview material, along with the team. I helped to re-tool a 100-page manual used for the study to focus on health and needs of people with mental illness.

And I sometimes do mock interview to help the researchers. I've had hands-on involvement in all aspects of this study.

Kelsi: Thank you, Paul. Pat, would you reflect on why the PAR model was a good fit for this study?

Pat: Well, let me put it in perspective. I've been doing research for 30 years, and I published my fair share of journal articles and books, and know a lot about this kind of stuff. And so, I could sit down in my office and rap out a study really quickly. But here's the reality – I'm a white guy who lives in the suburbs. So, what do I know what the experience is like actually living in the city, in this very diverse city, with all of its challenges, and what it means in real life to do it? And so, participatory action research not only starts with the issue of empowering people with mental illness to make sure we get their perspective on what we're doing. But again, to recognize these people often are ethnically diverse, perhaps challenged by such important issues as poverty or health, and housing instability, or food insecurities, or perhaps involved in the criminal justice system. Those are realities that challenge people who are trying to deal with their health, and so we try to put together a PAR team that will make sure we develop an intervention that reflects that perspective.

Kelsi: I'd like to hear from both of you for the next question. What have you done to ensure that PAR works well for your study? Paul, how about you go first?

Paul: Start with a level playing field. Everyone is an expert on something. Everyone's input is important. Every idea is considered and taken seriously. Not every idea is acted upon, but all views are considered. When everybody feels they can contribute, then people open up. They also become invested and want to stick with the study until it ends.

Kelsi: Pat, what about you? What are your thoughts on how you've made PAR work so well?

Pat: You know, one of the things that surprised me about PAR is I sort of come into this thinking, I know exactly how it's going, and I fool myself. I learn with the group as we go.

I sort of agree with what Paul just said. The group becomes a bit of a family, we develop some sort of cohesion, we get to know each other, and we get to trust each other, so we're willing to flip ideas out on to the table, and sort of try them out and see if they make sense.

Doing good PAR is a lot of upfront work. So, at the end of the day, we're trying to build partners, not research participants. I think the typical experience of people with serious mental illness when researchers come around is that they're supposed to be passive, and a researcher is going to ask them questions. And so empowering people, encouraging them to speak out, to be in a true partnership is one important challenge.

Another thing that PAR does for us is in doing research, there's a fundamental challenge of logistics. So, if in fact we're going to, for example, come up with a peer health navigator program to help an individual with mental illness go to the west side, north side, and downtown to deal with all their health problems, how do you exactly do that? Where does the public health system come in? Where can we use med cars or the like? People with lived experience, who are out there doing it, know really what that means.

Kelsi: The next question is also for both of you. How do you manage the different roles or ways people contribute on a study? Pat, how about you take this one first?

Pat: Well, again what we're focusing on here is a team of people. I would break the team probably into three groups. One is, by nature because it's research, there's a scientist on the team, who knows the methods and the measures and how to rigorously do things. But what makes us participatory action research is number two is people with lived experience, like Paul, who come in and tell us, "you know that might work well in a textbook, but that's not how it plays in the real world." And then, the third arm of this – it's important – are the service providers, because at the end of the day, the PAR team is going to come up with what we expect service providers to do.

You know, given the three sets of us coming at this table to put together a program, have some expectations in it already, one is being very mindful of the doctor role. Because, although it's probably not appropriate, frequently people come to the table and say, "he's a doctor, he's going

to tell us what to do.” And so, the first thing I really need to do is shut up, and make sure I don't suppress people's voices, so they feel comfortable to tell me anything. And, I actually know participatory action research is going well when people on the team first come up with things I never would have thought of, and second, come up with things I don't even like. Because that's exactly the point – I don't have that lived experience. That said, the participatory action research team has people who may have mental health challenges. And so, like anything else, we're hiring them as our partners, we expect to provide reasonable accommodations to them so they can stay involved over the course of study, and so we will do that.

Finally, as our partners, I get paid for my work and so people with lived experience on the participatory action research team get paid for their work. So, we pay them not only for the meetings – and meetings can be kind of demanding. When we start a project, we'll meet together 90 minutes to two hours a week for multiple weeks in a row. This peer health navigator project is for five years. We've been together almost a year already. In addition to that, as Paul suggested, will need people to go out and do some extra stuff. Paul makes himself available to test-run our interviews on our research assistants. So, in addition, we need to pay people for that, and we will do that too.

Kelsi: Well, going back to you Paul what do you think? How do you help people manage their roles on the study?

Paul: Well, it's more or less like, I come up with ideas. You know, I try to be open and encourage everyone to speak their mind. The team fosters the idea that everything is on the table, everything is open. Nothing is really off-limits. What we do is, we come up with an idea, we then try to work it out.

But one of the things is everyone is very accepting. For example, I needed to back off work on one of our trauma studies in the past. The topic was a trigger for me, so I decided to step away and nobody on the team made me feel guilty about it, about my second thoughts. I felt supported in that I tried to learn from it that it wasn't for me.

Kelsi: That's really great to hear how your own experience also informs how you work with other people in their roles.

Paul: Well right now I'm currently training someone else. And pretty much my part of the training is sometimes doing role play. Role playing certain roles and ideas and creating characters for them to interact with. Like a real-life environment, you know. They get to interact with someone with lived experience, they get the knowledge and wisdom of somebody who's been through some of this stuff that they're going to be doing.

Kelsi: Thank you. Pat, I'm wondering if you can speak to the challenges you've faced using PAR, and how you've overcome them?

Pat: I think one of the interesting things is that we're trying to get a group of people together to work. And so, it is a bit of work. Again, we meet two hours a week in between time. Paul, and

the team, and I, in the last couple months, revised a 100-page peer health navigator program to reflect the interest of people here. That is a bit of work. We do pay people for their time but, again, it can be a surprising hat for people because, usually the relationship in research is the expectation of the person with mental illness is they are going to be passive and asked a bunch of questions, and we do anything but that. We tell you to tell us the answers; tell us how to fix this kind of thing.

Another thing, it can be, it can be kind of hot and cold in terms of the amount of work we do. When we start, we tend to be very active. Because at startup we have a lot of decisions about what the intervention is going to be and how are we going to measure it and how do we cover research participant ethical concerns. And then things tend to quiet down a bit. In fact, in terms of the peer navigator program, Paul and I are in a bit of a quiet down period, and we're going to monthly meetings. Paul and I and the team have a meeting next Tuesday. Even though we're in sort of this recruitment stage, we really need the team to help brainstorm with us how to meet our recruitment goals, because even though it's a great study, we're not getting everybody into the study we would like to. We also have a training program for the peer health navigators – a program that Paul had a big role in. We need to back up and see whether the peer health navigators who are currently in the field want any additional training.

Kelsi: Paul, what is one thing you'd suggest to others wanting to try the PAR approach?

Paul: Knowing from the beginning that you get meaningful results from true involvement. So, it's worth the time and effort you need to put in to true participatory research. And you get the experience of being a part of something bigger than yourself. You get a real sense of accomplishment by doing this. But the challenge is it takes a lot of time, and it is a lot of effort.

Kelsi: Pat, what do you think next steps might be to encourage broader use of PAR in mental health services research?

Pat: Well, I'd like to come at this from two different angles. One is, we need to realize that PAR is the natural next step in the mental health field in the recovery-oriented services towards peer-driven interventions. Just as we realized in the work setting, education setting, the health setting, peer providers have huge value in terms of helping individuals reach their goal. They are in charge, they are empowered to work with the individual. So, we need to start the same thing in terms of research. We need to get people with lived experience as our partners in the research.

And here's why that's important. It's important when you start a study going into the research, because their years of lived experience help them understand questions that I, as a scientist sitting behind my books, don't even have a clue exist.

And here's why it's important coming out of a study – it's ownership. When we're all done. You don't look at this and say some white guy from the suburbs, who doesn't know a clue about what it means to live in the city, came up with this program, because it's not. It's a program of people, of eight to ten people with lived experience, who are our partners who grounded this out over time, and came up with intervention we're able to implement.

Something else to think about here, in talking to the scientists who are listening to this. You might wonder whether PAR is fundamentally biased, I mean, are we really doing research or sitting around the table with a bunch of patients who are telling us what the outcomes are? Aren't we really leaning towards filling in the answers we already expect?

Well, let's be clear, that is the nature of all kinds of science. When we're doing a study on a drug, the pharmaceutical company is betting upfront that that drug will work. So, if we're doing a study in peer health navigators, and we're doing it with peers, were betting on it and trying to develop an intervention that in fact represents their interests, with hypotheses that in fact represent good outcomes. So PAR is not a slippery slope, squishy approach to science. It's as rigorous as any kind of hypothetical deductive methods.

Kelsi: Well, thank you both very much, I really appreciate you taking the time to talk about PAR today.

Pat: Well, thank you. I want to reiterate something Paul said. I really am moved about doing PAR. I really enjoy our current group, meets 10:30 on Tuesdays. It really does make me think that the science is bigger than any one of us. It can be a lot of work. As a said, I can sit in an office and throw some ideas down really fast. As opposed to getting around with a bunch of people like Paul, and Paul is quite willing to tell me whether I got something wrong. But at the end of the day, first I build these really close, family like relationships with people and, second, we really pound out some important health and science issues.

Paul: I'd like to say thank you and I also have to add I think PAR is worth it, because I think you get better results for more people with lived experience. You know, they go through all the kinks and problems of it *before* it is implemented. You know, you have people who actually have to live with this and have lived experience from this.

And also, as a team what you get out of it – you get a sense of accomplishment. You know there's nothing better to see something that you worked on for the community and everything that you get to see from start to finish. There's nothing like it you know. So, you do invest in it, you do eventually become invested in the program, and once you're invested in it, you're going to try to do your best about it, you know. I'd like to see more of these programs, if possible. And if you're thinking about doing this, this is worth it. Thank you.

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