

UIC Participatory Action Research (PAR) Podcast Series
PAR in Action: Studying Wellness Recovery Action Plan (WRAP®)
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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.

Kelsi: Thanks for joining our PAR podcast series. Today, we will be discussing the roles that people with lived experience of mental health conditions played in the Center's research on the self-management model called Wellness Recovery Action Plan, or WRAP. I'm joined by Matthew Federici, a well-known and highly respected advocate, who is Executive Director of the Copeland Center for Wellness and Recovery. Also with us is Jessica Jonikas, Associate Director of the UIC Center on Mental Health Services Research and Policy. Jessica is a family member of people with mental health conditions, and was a co-investigator on the WRAP research that we'll be discussing.

Kelsi: Let's jump right in. Matt, could you give us a brief introduction to WRAP, and your involvement with it over the years?

Matt: Yeah, sure. So, WRAP stands for Wellness Recovery Action Plan. And essentially what Wellness Recovery Action Plan is, is an individualized approach and planning process that develops through a peer group. And that individualized plan is intended to help me be well, stay well, and get well.

My involvement, I have to say, you know, really coming from my own experience started in maybe my adolescent years with trying to get well and stay well, led me to discover some important life lessons. And with that, I kind of ventured off into a career of helping others in the mental health field. And, as I began to work prominently in the public mental health sector, with a lot of the theories and college-level education, and provider and clinical roles, it just felt like something was very amiss in the way in which services and supports for being engaged. So I sought out what I was starting to notice was a movement of peer-based -- people with lived experience -- helping one another. And also through many of the professional associations, seeing the research that was coming out on the effectiveness of peer-to-peer programming.

I undertook a project to train and roll out what's called certified peer specialists -- trained people with lived experience of mental health recovery working with others -- and a major component of what was designated in that curriculum of trained peers was this program called WRAP. And, as I started looking at that curriculum, I realized that WRAP really kind of summarized the 20% of things that I was doing in my life that was contributing to my recovery. It just really connected to me in a very simplistic and authentic way. And, as I began to be involved in doing these trainings, including WRAP, I could see that people in these courses were gravitating very much to this standard curriculum material.

And so this led me to join the Copeland Center for Wellness Recovery, which is an organization continuing the practices of this peer-facilitated group model, which University of Illinois at Chicago researchers did a participatory action research around.

Kelsi: Jessica, how about you? How did you come to know WRAP and become involved with the research on it?

Jessica: Thank you, and Matt, for sharing that experience, I really enjoyed hearing about it. I'm definitely showing my age here, but more than 20 years ago now I had the pleasure of meeting Mary Ellen Copeland when we invited her to speak at our First Self-Determination Workshop series. And the first thing that struck me was the turnout. Standing-room only wasn't something I had ever be seen before, for a workshop on mental health. It was very striking, we had people just lined up across all the walls to come hear her. And, listening to her speak, I quickly understood the power and the popularity of her messages of hope and recovery, which, at the time, frankly, were not prevalent in public systems. And, maybe, in some systems, still not there. The WRAP approach felt like something special.

So, our Center director, Judith Cook, met with Mary Ellen, and a participatory partnership was created to study the impact of WRAP at a time when there really wasn't rigorous research being done on peer-developed and peer-delivered models. At that time, there weren't many messages that people with mental health conditions could indeed self-manage their own health and wellness, while reaching out to others to help them do the same. So, for our listeners who are interested in this research that Matt and I have been talking about, we will be sure to post these articles with today's recording.

Kelsi: The intention of participatory action research is not only to gather information but to effect social change. Matt, would you reflect a bit on why the PAR model was such a natural fit for studying WRAP?

Matt: Yeah, thank you, that's a great, great question. I really do think that the PAR model is, it has so many layers, so many parallel benefits. WRAP was a great fit for this type of approach. Actually, I don't know if other, any other type of model of research would have worked well with WRAP. WRAP actually started off, you know, with Mary Ellen Copeland's leadership, very much in a grassroots, peer initiative, that is very in line with the PAR model of research to begin with.

So, you know, Mary Ellen, and her key peer, Jane, who both went through their own experiences, started off with a question. You know, "how do we get well and stay well for longer periods of time," which was a question and a solution that wasn't sought at that time. For the most part, if you were dealing with significant mental health challenges, the message people were receiving was to just manage, just manage it. And, they really posed a very participatory approach by saying, well, that's not good enough. "How do we get well and stay well? How do we move beyond these limitations we're experiencing?" and began a collaborative process with other people who were also interested in that question. But also started off from a basis that people with lived experience, people with differing perspectives, had some idea about this, how we can move forward in a constructive way and action-oriented way.

And, and so, this is very much in line with the values of a participatory research model. And, one key element from the WRAP experience, was that people with lived experience were involved, not only in the research, but in the delivery of the intervention. So, I think that contributes to the authenticity of the participatory research. And the acceptance of the studies of WRAP in the community really came from the fact that, in many ways, it was kind of piloted first, because people were collaborating. And, as they were developing the WRAP program, they weren't developing it in a way where it was a predefined set of beliefs or ideas that they were sought out to kind of prove, but rather to test in a very organic way.

You know, in short, I'd say WRAP was a natural fit for this type of research, because the values were consistent -- of collaboration, mutuality, and really wanting to seek out results. That people wanted to see results in their lives, so, you know, research is about actually looking at and seeing what results are really working.

Jessica: Thank you, Matt. I just, you made me reflect back on what was so interesting about it at the time is WRAP, by the time we had decided would be something certainly worthy of study, was already so popular. It was being used all over the world. So, in some sense, people could have said, "Who cares if we establish an evidence base for it. People are using it and love it, right?" But the fact that we were able to partner with this group, who really did want to know, what are the different ingredients that make it work. And let's establish that and show the world that it has this evidence, or maybe it doesn't. You know, one of the things doing research, you have to go in knowing, maybe we'll find it doesn't work. People like it, but it doesn't work. So, we had to stay open for that possibility, as well, but it's an interesting point, that it was already being widely used. So, introducing the research into it, I think PAR was really important, that it was going to have to be participatory. So thank you for that.

Kelsi: Yes, thank you. Matt, you talked about how people with lived experience are a key component of successful participatory action research. Are there any other key components that you want to talk about?

Matthew: Yeah, I think that's a really, really important question. I mean, one of the things that I value a lot about the program, the WRAP program itself, but also the kind of the shared values with participatory research, is that when people with lived experience of all kinds -- so we all have a different experience, particularly, you know, recovery, the challenges we faced -- we have diverse experiences within that shared challenge, right? When we involve the diversity of those lived experiences in the creating of the intervention, it's more likely to be informed by their culture, their values, and their perspectives, right? It's more likely to penetrate within the actual community, because people will see their values reflected in the approach. And we also know that the greatest, you know, the values conflicts that occur often -- and of course, we're at a time now where this is a big

discussion with the vaccine and the pandemic, certain communities and the trust level around that – when the intervention like WRAP, which came from diverse groups of individuals, continues to expand and include, and it's designed in a way in which any person's perspective on how they've gone about their recovery of various different challenges in their lives, can find a voice and a space in the program.

And also, when the intervention, it was being replicated and continues to be replicated, people can see that there's space for their values, they can see people whom they have authentic trust in. And we know, there's actual research that shows that, when peers from those communities are involved in, say, the dissemination of education around certain things, you know, the research is pretty solid that the credibility, the authenticity, the social modeling, is enhanced, right? However, what was good about the WRAP approach was that it wasn't, say, just involving peers in the dissemination, after the fact of an intervention they weren't involved in, about results that they were not a part of collecting the data on.

But just using peers in of itself is not enough. We know also that programs that the agendas aren't designed by the communities in which they affect the most, but designed by others outside of those communities, that even when they eventually engage peers from those communities to disseminate that, are not as successful.

They have to be able to choose how little or how much to participate, and they must have shared decision-making power in the process for what and how the intervention or services will be studied and replicated. And I think that's of mutual benefit to both sides.

So, again, I think, a really key component, what made this a very successful research project was involving people with a lived experience from beginning to end, and I think that's why here we are, you know, well over 20 years later, and we're seeing that, as far as Hong Kong, Canada, and now in Ghana, that people are saying this makes sense to me, this program works. And we're seeing, I would say, with some really strong consistency, versus a lot of other models I've seen where you can walk into the door and see such a variation on what initially was a very rigorous model has drifted. I would say that we've been very successful and having very little drift because of the personal connections people have to what we're doing.

Jessica: Matt, I was just reflecting on how, there's this idea that for some people, they want to shy away from the ideas of values in research, and for other people, they want to shy away from the idea of research as part of their values. And what was so nice about the PAR approach is it was a safe way to bring those things together. The values were going to be a part of it, research was going to be a part of it, and that's how we would show the world this worked, if it did, if that's what we found. So, I really appreciate that discussion about the value space.

I think some other things – it's very important to remain objective, because we do not want to bias any of the findings. But I do think that all stakeholders sharing a passion for the topic being studied contributes to the success of the effort. So, if things get bumpy as the team works through conflicting views or values, being able to fall back on a shared belief in the importance of the work can really be a project-saver. And related to this is the importance of building trust and relationship by setting a common agenda with all stakeholders involved in the participatory action research. So, we want to be sure we're transparent about the common goals we're all working towards. And part of this involves discussing in advance the outcomes that actually can be measured so that everyone understands what can and cannot be established by the research alone. And while I think we're seeing especially through this past year of the pandemic, that research is clearly important, it's not the only way to establish the value of a given intervention. My feeling is that if we see research as one part of a whole, we can value all aspects of the scientific, clinical, and personal evidence of the benefits of a given approach.

We've also found that it's important to clearly identify roles and responsibilities upfront as much as possible. That's not to say that people can't wear multiple hats, so to speak. But, if each of us isn't confident about our role and what we're contributing to the larger effort, that can cause confusion and even some resentment over time.

And then, finally, I'd say, once the data are collected and analyzed, of course, we want to collaboratively discuss the findings and their implications for both practice and policy. But we really want to step back and ask ourselves, why do these findings matter to the people whose lives are most affected? And why do they matter to policymakers and practitioners? Participatory action research helps us to ensure that we understand the impacts from all these different perspectives.

Kelsi: What does meaningful inclusion of people with lived experience in research look like?

Matt: Yeah, I think that as, you know, as I was kind of speaking to earlier, is really key that, you know, when people are involved both in programs, projects, interventions, what makes it meaningful is when it's really authentic. And one of the things that I think is pretty key is starting off as you intend to go. By involving people with a lived experience from the beginning to the end is really starting off from the perspective that what we really want to do is find out what is working well for people, and involving the people whom you're trying to reach with this is really key.

An evidenced-based intervention needs a story to make it stick. So, data is, particularly in the rigor that was done here by UIC, randomized controlled trial studies, the rigor, the numbers, the objectivity, is definitely meaningful from a scientific community, in understanding that this was objective. These were consistent, reliable, and valid approaches. You can have that, but it needs to then inform practices. It needs to then get out to the community. I think there's been some numbers thrown around that they can take 12, 17, maybe longer, between when research is done, and when it actually reaches the community, and impacts it. But when you involve people as a part of that process, who are kind of the end-receivers or beneficiaries of it, it helps in getting the story out about why and what is being done, why are we doing it.

So, the inclusion that we achieved with WRAP carried the stories to those for whom it mattered most, and allowed for the fidelity and replication, which we see now, as I said, you know, there's over 10,000 practitioners of this model. People believed in the story because they saw that they had inclusion. People like them had inclusion from the beginning. They saw that there was a genuine and authentic investment. There was no "behind-the-curtain" for people. And today, when we talk about the program, people who are introducing the program can tell the whole story. They can tell the story about how this began – you know, rural parts of Vermont, and then spread throughout the state of Ohio.

And, you know, going back to what Jessica was saying about, where do values play a role in all of this? I think one of the key elements, I remember coming across one of my mentors in the career, Dr. Bill Anthony, who was kind of considered to be one of the fathers of the Psych Rehab model. Once made a comment to me about how evidence-based programs are good, but how do we get new innovative programs if we're just replicating evidence-based programs? And he kind of answered the question, which is, you know, we need to take a look at the values, what are the practitioner beliefs? What are the values they hold in delivering those services and the practices that go along with that? And one of the great things about this program was that peers are people involved in the work. One of the early parts of the story was, um, the peer facilitators of WRAP asking the question, what are the beliefs that guide our practices, and how we kind of set up and facilitate the group? And identified, you know, core beliefs and behaviors that match those beliefs. WRAP, as far as I'm concerned, and the research that UIC did is one of the few programs that actually took some beliefs and values in an objective manner, and observed that there was consistent practices in accordance with those beliefs.

And, I think a lot of due diligence was done to break that down, and to make sure that that could be, you know, observed and measured scientifically. And it's the only program I know that really took a look at, a values-based practice, and was able to demonstrate it as an evidence-based practice.

Jessica: Thank you, Matt. Yeah, you are making me remember how hard we really did work on trying to figure out those different values and different ingredients that made WRAP work, so that we could study them in an objective way. And it, you know, could be difficult work, but it was very rewarding, but it was a big part of it. And I also love this metaphor of creating and telling a story together, because we can be objective about what is working or not working as we're creating and telling stories, but it's the story that holds us together. I just love that, thank you.

Some of the other things I think about in terms of meaningful inclusion are a little bit more logistical, but, one key thing that we, of course, worked on, was facilitating participation from all the members of our team, as was comfortable for them. And, we helped this along by discussing expectations in advance, along with what would happen when someone wasn't feeling well enough to participate. And, by discussing this in advance, we established a dignified way for people to take breaks if they needed to. And we were always sure to welcome folks back, and catch up, to where we were, if they needed a break for health, mental health, or any other reason.

I'd also say we needed to be willing to make some changes to the research intervention. If your partners in the field are reporting back to you that what you're doing isn't meeting needs or working well, you don't want to

assume it isn't hitting the mark because the participants have some kind of vulnerability. It's just as likely to be that the intervention needs some tweaks. So I think, as part of PAR, everybody needs to stay open to hearing what works and what doesn't work, even for interventions that we all embrace or we think are really great.

Kelsi: What would you both want researchers to know as they engage in PAR?

Matt: This is a great question – you know, what to know from this experience.

I would say, as I spoke to earlier, just how important it is, like UIC that took the time, not only to involve the authentic peers in which, you know, these programs are intended to serve and support, but to get to know the values of that community. And I think that can some take some time, because there, you know, there's a value to research and values that come with the research community, and what research is attempting to do and not do that, I think, is mutually-beneficial for both groups. So, whatever research that you're looking to do with a particular community group, I think really exploring the shared values there, but really getting to know and taking the time to know what those values are and how that impacts the intervention you're testing, how it impacts how this might get replicated or not.

So, you know, the modeling, the authentically asking the question, how do we not only talk about how important it is to be empowered, each on our own individual level, but how do we create an environment where people could see that happening in the group? You know, we didn't want the research at the same time to dilute what we thought were the key ingredients, so we had to take the time to really figure that out, to create the fidelity. The fidelity assessments that included those values was, I think, what was pretty substantial about WRAP in particular, and again, as I said earlier, I just don't think any other research approach, but the PAR approach would have fit that. So it wouldn't take much to convince me that whichever population you're trying to develop, or test an intervention around, that you'd have to take the PAR approach if you really wanted to see efficient dissemination of what was working in reality in people's lives.

So for me, I think that's one of my pet peeves is going out to work professionally in the field of mental health, was getting familiar and finding research programs, and things that were working and then not seen them actually either, A) in application and funded programs, or B) they were there, but the fidelity wasn't consistent. And one of the things I love about this is how committed everybody is, to not only the information and the program, but this whole storyline, this whole story that everyone is very familiar with that has both informed, you know, people in the community that are trying to get well and stay well and dealing with these very difficult things. But really kind of bridging the gap between the research community and the communities we're intending to impact.

Jessica: Yeah, that's really helpful, and I think one of the key things you were talking about was taking that time. I remember really, just needing to take the time to get to know one another, and build that trust. That was really important, so that there were times when we had to say, "No, that's just not going to work from a research perspective." And we knew that the people we were working with and the WRAP community could hear that because they trusted us. And then there were times when they would have to say to us, "No, that's not going to work from our values perspective, or from what we believe is magical or works about WRAP," and we had to be able to hear that as researchers.

And, I think the time we took to get to know one another was a big part of being able to move forward and do that. So, I think everybody really has to be willing to change and grow as you tell the story together.

I think it is critical for researchers, of course, we have to make the process and outcomes measurable. That's always the big part of getting published. But the intervention and the experience need to be authentic to the lives of the people who will be most impacted by the research findings, so that work to line up what is measurable with what is authentic can definitely be a struggle. But it was so worth it and I think it made for a lot better research. And again, PAR, that PAR framework, really helped us to be able to do that.

Kelsi: This has been really informative. What can you both say about next steps for PAR and WRAP?

Matt: Well, I think it would be great for someone to document the impact that PAR has on the peer researchers. You know, how does being included in meaningful ways help people hone their own self-evaluation and self-advocacy skills? You know, do they learn about themselves and their work in new ways after being involved in PAR? Do they carry that experience to other aspects of their work? I mean, one of the things that I really have benefited in my own process of recovery and getting well was, you know, in education. I think, seeking higher

education and gaining what education brought for me is how to really kind of evaluate things in my life, how to gather more information. Essentially, you know, how to be a researcher in my own life and the value of that. And so, I think that WRAP kind of models that because it came from a grassroots question that Mary Ellen posed – “maybe we could figure this out.” And she really took a very organic kind of research perspective to it. And so you know the next level is when you're involved in a participatory research model like this, and I think by including peers, whichever community you're trying to impact in the process, I think there's an outcome in just being a part of that process.

Again, as Jessica said, there was a lot of going back and forth, and explaining on both sides from each community why something was important, and why may it not. And there was trust, but I think there was also patience to educate one another. And so, I think, you know, really, a big next step is to see, well, there's probably some positive impacts in just being included in that process.

Jessica: I completely agree. As a researcher, my life and work were so strongly impacted by working with Mary Ellen and the WRAP facilitators in those early years. We all learned so much from each other and I think it'd be an interesting thing to study. As just one example, Mary Ellen made sure that WRAP's core concept of unconditional high regard was a touchstone for every aspect of the research and the intervention. You know, I personally was educated in the early 80s and early, sorry, in the 80s and early 90s, when people who are struggling to be in a class or in a group would probably just be excluded. But Mary Ellen would bring us back to figuring out, well, what had happened in life for that person? What was going on with that person? And what strengths could we identify to help that person move forward? And unless there was imminent danger, exclusion was just not an option. So that kind of high regard is an idea I've tried my best to carry forward to other research and educational endeavors across the years and, really, to my own life and my parenting. It was very impactful for me. So, I think, as Matt says, studying the impact of participating in PAR, including on the researchers, everybody involved, would be really interesting and informative.

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

Jessica: Oh you're welcome.

Matt: You're very welcome.

Jessica: I enjoy having the opportunity to just reflect back. It's hard to believe how many years have really gone by since we first started doing this work together, and just all the ways that it's evolved and the impact it's had personally and professionally. It's really a pleasure to talk about it and be here with Matt.

Matthew: Likewise, I appreciate the opportunity to, you know, to talk about this and always to partner with Jessica. And yeah, just to keep coming back to the, to the story, what happened and how it happened. It always gets me, re-engaged in the work and just how many dedicated and, you know, committed individuals were involved. And I just, I like being involved in communities of collaboration with diverse perspectives. And this collaboration over 20 some years has been the most authentic example of that. So, appreciate the opportunity to talk about it.

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