

# Reflecting on Participatory, Action-Oriented Research Methods in Community Psychology: Progress, Problems, and Paths Forward

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## Highlights

- Participatory action research (PAR) remains an underutilized methodology in community mental health.
- PAR embodies the type of approach needed to improve the system-level impacts of community psychology.
- The contexts of PAR are changing and how PAR is understood and taught need to change with them.

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**Abstract** This paper provides a critical reflection on participatory action research (PAR) methods as they pertain to community psychology. Following a brief review of the fundamental aspects of PAR, key developments in the field are examined. These developments include the redefinition of the research enterprise among groups such as Indigenous and consumer/survivor communities, challenges that attend the “project” framing of PAR, academic and practice context challenges, and important domains in which PAR methods need to become more engaged (e.g., social media and disenfranchised youth). Three illustrative case studies of programs of work in the areas of youth homelessness, consumer/survivor engagement, and Indigenous research are provided to illustrate these contemporary challenges and opportunities in the field. The authors make the argument that without an effort to reconsider and redefine PAR, moving away from the stereotypical PAR “project” frame, these methods will continue to be poorly represented and underutilized in community psychology.

**Keywords** Participatory · Action research · Participatory action research · Community psychology · Methods

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## Introduction

If you have come to help me, you are wasting your time. If you have come because your liberation is bound up with mine, then let us work together.

(Aboriginal activists group, Queensland, 1970s, 2008)

As community psychology researchers, we welcomed this call for submissions as an opportunity to reflect upon our experiences with one of the more established and yet problematic tools of our trade—participatory action research (PAR). Note that while we use the term PAR and have it as a focus, this discussion has considerable relevance to newer and highly inter-related if not interchangeable framings such as community-based participatory research (CBPR), collaborative research, participatory research, social action research, and community-engaged research (Kral & Allen, 2016).

While much has been written about PAR (e.g., Brydon-Miller, 1997; Kidd & Kral, 2005; Kondon, Pain & Kesby, 2007), this critical review is timely, from our perspective, for several reasons. It is a counterpoint to the research-to-practice inroads that have happened through randomized trial methods in community-based interventions such as supported employment, supported housing, and assertive community treatment (Corrigan & Mueser, 2016). Clinical trials in these areas have brought a focus to community-oriented interventions in a manner not seen since the first wave of deinstitutionalization (Scull, 1976). What has become increasingly obscured, however, are the agendas, experiences, and actions of those directly affected by mental health challenges in this culture of randomized trials and expansive and uncritical use of the constructs of “community” and “recovery” as treatment and policy objectives

(Kidd, McKenzie & Virdee, 2014; Kidd et al., 2016a,b). In this context, participatory research approaches remain comparatively marginal although some promise can be seen in the modest but nonetheless noteworthy proliferation of specialist journals attending specifically to participatory designs (Journals for Participatory Research, 2017).

Another reason for the community psychology field to reflect on PAR lies in its fundamental nature. In one of his last academic talks given before his death in 2008, Orlando Fals Borda, a foundational PAR scholar, reminded us of the embeddedness of PAR in social, political, and cultural change and struggle (Fals Borda, 2008). Whereas most dominant methodologies imply or directly promote an ahistorical and objective stance, or as critics might put it a “view from nowhere” (Nagel, 1989), PAR is fundamentally different. PAR embraces a social justice agenda—coming from *within* communities wanting to apply research, action and activism to problems (Fals Borda, 1991; Fals Borda, 2008; Torre & Ayala, 2009). It is woven into historical, social, political, and environmental contexts. As such, the question is less about whether PAR as a set of methods has changed with time. The question is “Has the world changed?” We argue that it has—radically in fact—and that the conversation about PAR has changed along with it.

It is our intent, therefore, in this paper to describe what would appear to be some important developments and considerations that have emerged in the PAR literature and in the conditions that affect PAR. We provide a brief overview of the history and core methods that attend PAR and then move on to describe some methodological and contextual developments and their implications for community psychology. We then use our careers in participatory engagement to help illustrate the points made and share how our perspectives have shifted over time. We argue that participatory engagement in research, and the social action that can result from it, are critical levers to advancing community mental health.

## PAR Foundations

At its most fundamental level, PAR is a dynamic process of knowledge generation and sharing paired with action that happens within the frame of consciousness-raising or “conscientization” (Reason, 1994). This work sits on foundations established by people such as Paolo Friere and Orlando Fals Borda whose activism in the 1960s in South America began with education and awareness-raising as vehicles for change for oppressed people (Fals Borda, 2001; Friere, 1970). This step is essential to “disindoctrination,” or the recognition that the information and skills that are readily available in a given society often serve to sustain, rather than address, inequities

(Grossi, 1981). Building from these principles, people involved in PAR projects enter into them as co-researchers. While in practice one or more of the researchers might come from a formal academic background and institution, their role is to study a given problem *with* those involved, and to become involved in cycles of defining problems, gathering and sharing information, determining actions and studying what comes of those actions. PAR thus aligns with the core values and activities of community psychology—which is concerned with how individuals and systems interact to produce health or illness, with social justice, change and inclusion, and with individual and collective empowerment (Townley & Sylvestre, 2014).

While the practice of PAR can vary greatly in its details from one project to the next, there are a number of core features. It starts with the need for action to address an inequitable situation. In an earlier work of ours, we argued that this need must, in turn, be met by researchers with the right sort of “attitude” (Kidd & Kral, 2005). That is, researchers who can engage a group of people facing a problem, offering to put their expertise at the disposal of the group and rigorously applying PAR principles such that power and ownership sit with the group rather than the academic (Yeich & Levine, 1992). Researchers must approach PAR with humility, openness to learning, and respect for the legitimacy of the participants’ own perspectives and expertise related to how knowledge can and should be generated (Rahman, 1991).

With these key ingredients in place, the reflexive cycle of PAR then begins—the sequences of gathering and reflecting as a group, planning action and inquiry, acting, observing and recording, and returning to reflect further (Kemmis, McTaggart & Nixon, 2014). This process *is* the method and the researcher works within it as an involved participant—not as an observer or convener. The emphasis is upon action rather than knowledge generation—which inverts the more common research agenda in which action tends to be secondary and described as “knowledge exchange.” Specific methods of inquiry can be diverse across studies and can change over time within studies, though in practice, the inductive and more reflexive nature of qualitative methods tend to be applied to a greater extent (Kidd & Kral, 2005).

## Contemporary Issues and Community Psychology

In re-reading some of our earlier work, a problem with framing becomes apparent. It is a problem that is evident in many of the papers and books describing PAR, as authors grapple with covering the values of PAR and its history in activism and the pragmatic task of explaining

how to do a PAR “project.” Indeed, the writing of people like Fals Borda (1991); Fals Borda (2008) contrasts quite sharply with circumscribed descriptions of academic researchers engaging communities about a problem over the course of a few years in a manner more quality improvement than revolution. The persistence of such a research “project” narrative is fundamentally at odds with PAR and feeds into the critique that PAR projects often cannot sustain ongoing and meaningful participant engagement while running on too long in the framework of academic publication, grant, and career timelines and deliverables (Kidd & Kral, 2005). For us, as well as for many PAR researchers (e.g., Fine, 2013), this work is much less about projects and studies than it is about living the PAR “attitude” that we wrote about over 10 years ago—using participatory ways of working to make a difference *with* marginalized communities. It is about PAR careers rather than PAR projects. It is about relationships established with key community stakeholders over many years as projects, grants, and positions come and go.

This deeper type of engagement has ethical as well as practical implications. In contexts of wicked problems—or problems that are deeply systemic, interlaced with other problems, and multi-faceted (Conklin, 2006), it is arguably what Kim Hopper referred to as a misleading “reckless” type of hopefulness to talk about social transformation and inroads into inequities in the frame of peer-reviewed projects (Hopper, 2007). The poor mapping of this intent onto the single study framework might indeed account in part for the current critique of many PAR projects in that they poorly describe the cyclical process, do not appear to be fully action-oriented, and directly or indirectly frame those involved (other than the academics) as passive participants (Langlois, Goudreau & Lalonde, 2014; Munn-Giddings, McVicar & Smith, 2008). This mismatch might also account for the ongoing observation of problems in developing genuine PAR collaborations and being undermined by “community gatekeepers” through a poor understanding of the relevant local politics (Smith, Bratini, Chambers, Jensen & Romero, 2010). In contexts of long histories of extreme resource deprivation, marginalization, and systemic challenge, conversations about addressing systemic inequity through research by an outsider can seem hopelessly naïve and insulting.

Another area where our thinking about PAR and the field as a whole has changed has to do with changes in the groups engaged. Marginalized communities are becoming more active gatekeepers with respect to who they will engage with and around what topics. Such communities are also increasingly developing and driving their own research agendas. This is shifting the demand for the technical knowledge of outsiders and is reshaping how partnership occurs. Prominent among such groups are

psychiatric service users (consumer/survivors) and the associated development of mad studies academic programs (LeFrançois, Menzies & Reaume, 2013) and Indigenous communities (Stewart, 2009). These and other groups are requiring specific values and process orientations for engaging (e.g., feminist; Langan & Morton, 2009) and are overtly critical of the agendas of outside academics.

There would also seem to be some important considerations for where PAR is not happening. For example, unemployed, underemployed, and otherwise marginalized youth represent populations that are amongst the most disempowered and disenfranchised (Thern, de Munter, Hemmingsson & Rasmussen, 2017). They are groups that interact and engage primarily through social media networks. Yet, it would appear that PAR has very little substantive presence among such groups and through online communities (aside from a few noteworthy exceptions; e.g., Flicker et al., 2008). For marginalized youth and many other groups, the historical if somewhat stereotyped PAR model of engagement through circles of chairs in community centers has rapidly lost relevance.

Randomized trials and interventions studied therein are another domain in which participatory engagement is absent or unclear. This is of particular relevance to community psychology and community mental health given the influence of such trials on funding and policy decisions. Although echoing a decades old problem (e.g., Scull, 1976), it is of interest from an equity and action perspective that trial evidence more at odds with public/policy sentiment would seem far less impactful (e.g., the ineffectiveness of community treatment orders, Burns et al., 2013; antipsychotic medicine trials in remitted first episode, Wunderink, Nieboer, Wiersma, Sytema & Nienhuis, 2013). Herein lies a fundamental limitation of objectively framed trial research and is a space where the “counternarrative” of PAR is very much needed (Ledwith, 2017).

Despite this challenged context for PAR, we argue that these methods are particularly relevant in a sociocultural context in which marginalization and disenfranchisement are extremely prevalent and only increasing (e.g., Masri & Senussi, 2017). We argue that PAR methods need to evolve to consider the needs of contemporary community psychology—the changing demands of marginalized groups, changes in how social problems are considered, and academic contexts that are less and less conducive to this model of research. Indeed, the need for community psychologists to move this agenda forward is all the more urgent in community mental health where clinical trial-driven advances have made little difference in staggeringly high and in some contexts worsening rates of morbidity and mortality among people with severe mental

illness (Hayes, Marston, Walters, King & Osborn, 2017; Olfson, Gerhard, Huang, Crystal & Stroup, 2015). To this end, we present examples of PAR that grapple with some of the issues outlined above. We present an example of engaging homeless youth whose inherent stability and complex forms of marginality require a flexible application of PAR. We then present an example of a program of work with community psychologists and mental health service users engaging on issues of care quality and community inclusion—addressing efforts to move beyond tokenism to meaningful collaboration with politically active communities. Finally, we present an example of work that engages Indigenous peoples in efforts to prevent suicide, highlighting how PAR can be adapted to increasingly empowered individuals with multi-generational histories of colonial violence and exploitation. In each of these narratives of our careers in participatory research, we address three themes. We describe a process of steadily deepening engagement in PAR across multiple projects and initiatives—a process of growth through learning from our collaborators and *unlearning* assumptions and expectations that impede engagement. We describe our experiences at the point of engagement with marginalized communities—navigating mutual understanding, contributions, and the benefits of involvement. Lastly, we summarize our results to date in each of our trajectories—where there have been gains in areas of inclusion, empowerment, and fostering recovery and where we have failed or otherwise fallen short.

### Participatory Engagement of Street-Involved Youth: Kidd & Frederick

Youth homelessness is a pervasive social problem with complex social, psychological, economic, and political dimensions. It is an area in which few effective intervention models have been developed and studied and in which the literature has concentrated on individual-level, quantitative descriptions of risk that have proven to be of very limited impact (Kidd, 2012). Yet, in this grim situation in which so many hundreds of thousands of young people are traversing pathways characterized by severe marginality (Gaetz, O’Grady, Kidd & Schwan, 2016), there are all of the ingredients of impactful participatory engagement. These include (a) the activist-oriented, creative energy of street-involved youth; (b) a major social justice problem; and (c) public and policymaker contexts readily engaged by youth with ideas.

We saw this potential early on in our research careers. It started with the experience of intensive engagement in more traditional qualitative research—hearing youth obviously craving social justice and sharing incredibly difficult

experiences, ideas, and a passion for change (e.g., Frederick, 2012; Kidd & Davidson, 2007). This was taken a step further in Kidd’s work in the early 2000s, adding a blank page to a survey on which over 200 participants could write or draw any message that they wanted the public to see (Kidd, 2009). Participatory engagement also happened in small ways in many unpublished education, awareness-raising, and service improvement efforts through this period. In a lot of ways this was work that happened in “fits and starts” or, rather, short periods of participatory engagement with varying degrees of success in pushing for change—be it an improved service approach such as better screening for suicidality, informing a policymaker about key issues, or getting a public broadcast slot to do some awareness raising.

Compared with traditional PAR methods, this is a very limited depth of engagement—one that reflects a number of substantial challenges in engaging homeless and street-involved people in participatory research. These challenges include instability/mobility, inquiry fatigue from routine surveying by researchers and care providers alike, and an (understandable) suspicion of researchers and institutions. While we cannot claim to have solved the fundamental engagement problems outlined above, we have had some successes amidst the failures. These successes have happened mostly in the past 5–6 years as we have come to better understand how to adapt PAR for highly marginalized and transient people. Here, we have sought to capture what we have learned and, just as importantly, unlearned. Herein is the lesson that PAR can be just as much about researchers getting out of the way (i.e., dropping erroneous assumptions and subtle expressions of power) as it is about getting engaged.

Our recent participatory work has grown out of a mixed-methods study of youth exiting homelessness (Kidd et al., 2016a,b). It is perhaps not surprising that our deepest dive into PAR grew out of our deepest dive into the lives of these young people. It was in the period between 2012 and 2014 that we came to know very deeply and in some respects became involved in the lives of just over 50 youth—engaging four times over a year and seeing strength, creativity, and small bursts of momentum routinely thwarted by systemic adversity and personal trauma. Engaging at this level sharpened, for us, the disconnect between the depth of this social problem and the weak tools of traditional research knowledge translation. By this, we mean the academic two-step of publication coupled with the catered, powerpoint and report-heavy, stakeholder events—events that people do not learn well from, or do much following (Bannister & O’Sullivan, 2013).

Accordingly, we began conversations with youth in which we reflected on our mutual interest in more impactful engagement. In considering vehicles, they engaged

most around the idea of developing a comic with which to explore key narratives of exiting homelessness. Along with the comic format, our youth partners were drawn to discussions of intensive collaborative engagement over a brief and manageable time period (five meetings over 2 months), facilitation by a highly skilled activist comic artist who herself had experienced homelessness, and some informing of process by a senior comic artist with Marvel (itself exciting). Three youth ended up engaging in great depth—over five meetings working with the artist and with facilitation by Frederick creating a plot, characters, and dialogue that grew out of their experience and qualitative data from the study. The process seemed successful though did not lack challenges.

Stability issues among the group members meant that we rarely had a full group at meetings. This instability imposed a time pressure as did the grant deadline in which we were operating. The comic was nonetheless produced (Homeless Hub, 2017), and it became readily apparent to everyone involved that it conveyed powerful messages. Co-creation went on to developing a formal launch of the publication, a forum attended by over 200 people that included catering by a youth-run social enterprise, two publically broadcasted interviews, youth performances, and a powerful story telling session by one of our participants. These outputs impressed a number of senior policymakers and were instrumental in securing seed funding for a program of work now underway that is assessing intensive tertiary prevention supports for youth in transition out of homelessness (O'Malley, 2017). While the original youth fell away from this work, new cohorts have (a) become equal partners in service design and delivery; (b) moved forward a pure PAR initiative in the form of a by-youth-for-youth survival guide (Teresa, Cynn, Marian, Madeleine & Kal, 2017); and (c) become a central part of our substantial success in reaching senior policymakers, the media, and engaging funders. Indeed, our success in rapidly forging a partnership with an Indigenous community in northern Ontario can be attributable in no small part to how young people are engaged in this work. At a recent meeting in this community, an elder essentially said that such participatory, peer-driven engagement was the Indigenous "way of doing things."

There are a number of lessons that we have taken from these and other experiences with participatory engagement of youth. The first lesson lies in the areas of incentives and compensation. Like many working with vulnerable populations, our initial vision focused on basic needs and compensating the peer workers through honorariums, transit tokens, and meals. Although it is important to focus on supporting basic needs, through conversations with our youth collaborators it was clear that they were looking for much more. This meant moving beyond basic supports to

thinking about how to support and connect youth with certified training opportunities, networking chances, professional development, and career opportunities. Another key lesson concerns what it means to fully include marginalized youth at the table. On the one hand, time runs quickly—both in terms of grants and in terms of engaging youth in small windows of stability/opportunity before a life change sidelines their involvement. Maximizing time and engagement opportunities are critical for youth to gain the confidence and understanding of the work—how they can contribute, how they can register concerns, and what is the consensus on focus. In our experience, we have found many young people to be very adept at engaging quickly and assertively in these windows of time when their circumstances make it possible. On the other hand, there are those who work at a different pace (both by disposition and by circumstance) and in these instances time runs more slowly. Required there is a more artful maintenance and exploration of engagement for a group whose trust is difficult to earn but whose contributions can be extremely important. In these instances, one must be nimble, accommodating both circumscribed and deep involvement, having a project focus that quickly delivers tangible benefit, and processes that tap creativity, humor, productive anger, and compassion.

One final and related takeaway from our experience is the need to consider PAR with street-involved individuals as, in effect, multigenerational—with youth coming and going over many years, progress made in small increments in a slow curve of continual learning, and our most important contribution being the holding of information in a role that might best be characterized as PAR archivists. We can hold a base of youth generated knowledge and action, facilitating its being handed from one youth and one group to the next.

### **Mutual Support and Research Among Consumer Survivor Communities: Davidson**

My experience with participatory research involved a similar progression of deepening participatory engagement as Kidd and Frederick's above, as well as serving the multiple objectives of enhancing the empowerment of those involved, attending to rights advocacy and awareness raising, and improving service design. It is an area, however, that has a longer history—one dating back to the birth of the field of community psychology. During the earlier era of de-institutionalization, this work involved close collaborations between community psychologists and participants in and proponents of self-help/mutual support groups that attempted to provide an alternative to conventional mental health services (e.g., Borkman, 1990, 1991;

Humphreys, 1997; Humphreys & Rappaport, 1994; Kyrouz & Humphreys, 1996; Maton, 1987; Maton & Salem, 1995; Rappaport, 1993; Rappaport et al., 1985; Salem, Seidman & Rappaport, 1988; Tebes & Kraemer, 1991; Toro, Rappaport & Seidman, 1987; Zimmerman et al., 1991), having both research and advocacy aims. More recently, community psychologists have played leading roles in researching and promoting “peer support” as a next generation of interventions that hoped to bring the benefits of mutual support into the mental health system (e.g., Chinman, Young, Hassell & Davidson, 2006; Chinman et al., 2014; Davidson et al., 1999; Salzer, Schwenk & Brusilovskiy, 2010; Salzer & Shear, 2002). The action research conducted by my colleagues and I have evolved within this context in involving persons in recovery in more and more substantive ways over time (e.g., Davidson, Bellamy, Flanagan, Guy, & O’Connell, 2017).

Our first series of studies beginning in the early 1990s focused on the role of the hospital in the treatment of persons with serious mental illnesses. This was during the final days of de-institutionalization, when the failures of this ambitious but unfunded policy began to lead to calls for reversing course and recreating “asylums” for people who were having persistent difficulties in adapting to life in the community. Within this context, it became evident that of the hundreds of articles and books published about de-institutionalization since the 1960s, there were very few studies that had asked the people most directly impacted by this policy—the patients themselves—for their own views on the matter (Davidson, Hoge, Godleski, Rakfeldt & Griffith, 1996). While this degree of involvement may seem minimal from the perspective of participatory action research, at the time we were met with much skepticism regarding the ability of such persons to contribute their perspective to the emerging policy debate. When asked, however, long-stay patients who were being discharged were not only eager to share their perspective but helped us fairly quickly to realize that our key question—of where would you prefer to be treated, in the hospital or in the community—was both simplistic and off the mark. While they did express a strong preference for community, their stories were more focused on the similarities between, and limitations of, both settings than on their differences (Davidson, Hoge, Merrill, Rakfeldt & Griffith, 1995). Moreover, what was important to them was not where they were to receive care, but rather what they could do with their day-to-day lives, which were characterized as lonely and empty regardless of setting.

Two things, among many, that we learned from involving stakeholders in this study were that their perspective was very different from that of the practitioners and policymakers who were making decisions about their care and that, when asked, they appreciated having the opportunity

to provide compelling stories about the impact of those decisions in their lives. They were less concerned with where they lived and more concerned with how they lived, with each setting offering some advantages. The community was closer to home and family and offered safety, privacy, and freedom, but in its current form it left people feeling terribly alone, hopeless, and helpless, and at risk for medical conditions and complications. The hospital offered access to medical care and peers, but was experienced as unsafe, offered little privacy, and left people feeling that they had no control over their lives. Clearly, much work remained to be done in developing services that would enable people to reap the benefits of community living accessible to other citizens.

In a second study, we took the additional step of involving persons with mental illnesses in exploring possible strategies for overcoming the limitations of community-based care. We invited them to collaborate in designing and evaluating ways of enabling them to lead more meaningful and satisfying lives in the community. The presumptive target for this study was the problem of inpatient recidivism, which refers to the fact that some persons with mental illnesses, at some times in the course of their lives, cycle rapidly through multiple admissions to acute inpatient units (Cotterill & Thomas, 1993; Pfeffer, O’Malley & Shott, 1996). Despite a body of research that showed that the major factors precipitating readmissions were social and contextual in nature (as opposed to personal or clinical; Appleby et al., 1996; Green, 1988; Kent, Fogarty & Yellowlees, 1995; Kent & Yellowlees, 1995; Klinkenberg & Calsyn, 1996), the conventional approach involved attempting to identify and intervene early in the course of relapse to prevent readmissions. This approach was based on the belief that people were readmitted due to exacerbations of the disorder, therefore focusing solely on monitoring for and treating symptoms.

When asked about their views on the matter, participants in this second study—similar to those in the first—had a different perspective from that of practitioners and policymakers. As one participant remarked when asked about these relapse prevention efforts, he did not see how focusing solely on symptoms was going to lead to anything positive at all, much less preventive (Davidson, Stayner, Lambert, Smith & Sledge, 1997). From the perspective of stakeholders, we were asking the wrong questions and focusing our efforts on the wrong things. The focus of our questions was on what the outpatient and inpatient staff, and the person him or herself, could do, to avoid coming back to the hospital after discharge. It became evident quickly, once again, that these questions reflected the agency’s agenda rather than the agenda of the people being served. They saw no point to keeping people who were having significant difficulties out of the

hospital (i.e., is not that what the hospital is there for?) and were much more likely to talk about everyday challenges of living in the community without needed material resources, safety, and support than about symptoms or relapse (Davidson, Stayner, Chinman, Lambert & Sledge, 2000).

Involving these same people in generating alternative approaches to improve care has since led to a series of program development and evaluation efforts in which persons in recovery have come to play an increasing number of roles, both in their own advocacy and self-care (e.g., Davidson, Ridgway, O’Connell & Kirk, 2014) and in supporting other people who are earlier in their recoveries through peer outreach, engagement, and various forms of support (Davidson, Bellamy, Guy & Miller, 2012; Sells, Davidson, Jewell, Falzer & Rowe, 2006). At the same time, governments and research institutions in North America, Europe, and Australia/New Zealand have increasingly promoted, and begun to require, involvement of primary stakeholders (i.e., “patients”) and family members in all areas of medical research and in all phases of research, from serving as advisors or consultants to convening their own research teams as principal investigators—the Patient-Centered Outcomes Research Institute (PCORI) being perhaps the most prominent example in the United States.

We would like to bring this section to a close with an example of this last possibility, in which persons in recovery lead and staff their own research. Having the privilege to consult to and work with such a team has been one of the highlights of my career to date, and hopefully represents an early step toward a future in which persons with health conditions no longer have to be “invited” to the research team by well-meaning others because they will already be there. In psychology, in particular, this may require more self-disclosure among established researchers who kept their own history of mental illness secret (e.g., Corrigan, Larson & Michaels, 2015) as well as recruiting into the field young people with lived experience.

In my case, I was invited by a regional mental health consumer evaluation committee to assist them in designing and carrying out a project that would give voice to their perspective and which, they hoped, would have more influence on state policy than the projects they had conducted in the past. The reports from these projects, they were convinced, had merely ended up in policymakers filing cabinets, if not trash cans, and had no impact on services. After a brief discussion of the various options open to them, given their interests and resources, the group of eight decided to collect oral histories from 80 of their fellow consumers, as the group members committed to collecting 10 narratives each. For this purpose, they received training in qualitative, narrative interviewing and

in short order had produced 80 narratives, which they then transcribed. At this point, they decided that they did not want to entrust anyone else with the rich data they had collected, and asked for additional training in data analysis. After two fairly intense and evocative workshops—in which, for example, tears of recognition and empathic resonance were shed—they divided into four teams of two and set about the time-consuming work of producing individual narrative summaries of each interview, coming together again in a series of workshops to identify and elaborate on common themes.

At this point, the next challenge arose of what to do with their findings. While they graciously agreed that I could develop a submission for an academic journal to which they would contribute as co-authors (Davidson et al., 2010), they wanted their work to have a more immediate and direct impact on policy and practice. After again reviewing the range of options open to them, and being inspired by a similar project they learned about from Canada (Schneider, 2010), the group decided to produce a live performance piece based on the collected stories. The first performance was delivered to a large audience of legislators, policymakers, system managers, practitioners, family members, and fellow consumers, and elicited an enthusiastic and sympathetic response from all parties. Following this very gratifying debut, the group made the rounds of the state for an additional 2 years, giving this performance to a diverse range of groups, from high school students to public servants to residential staff. The main gist of the presentation—that even people who have benefited from care and whose symptoms have abated, need a map, guidance, and support to reclaim a full life in the community—continues to influence policy and practice, as the state system (in Connecticut), and an increasing number of systems around the world, shift from viewing recovery as solely an individual journey to contextualizing it within the framework of reclaiming citizenship in the community (e.g., Rowe & Davidson, 2016).

### **Participatory and Culturally Relevant Research Within Inuit Communities: Kral**

My work, while sharing similar themes as my colleagues above of a deepening program of work, awareness raising and grassroots intervention design, and seeing the increasing autonomy of the stakeholders involved as Davidson experienced, has been fundamentally different as a function of it evolving in an Indigenous cultural context. There, with Inuit in Nunavut, Arctic Canada, it has been PAR all along since 1994. Much has been written about suicide and suicide prevention, as Inuit have one of the highest suicide rates in the world. In Inuit communities,

suicide occurs primarily among youth and, as in most of the world, primarily among males. The first project began during a national suicide prevention conference in Iqaluit, Nunavut. I was asked to be on a panel on research on suicide in the north. I was the only non-Inuit on the panel, and we decided to ask the audience, which was mostly Inuit, for their suggestions for research. We did this, substituting “knowledge” and “understanding” for research, and many Inuit gave their suggestions. Ideas for what to study included finding out what made people happy or sad, what healing meant, asking about their health and about culture change, and asking about suicide—why young people are doing it and how to prevent it. We then asked the audience how we would go about getting this knowledge. It was suggested that a collaborative approach should be taken, to include Inuit youth, elders, and community workers, and researchers from the south. We would work together as one team from the beginning. I took many notes. This was my first learning of participatory research; I later discovered a thing called PAR, but I first learned it from Inuit. This was their way, an Indigenous method. At the end of the conference, a number of us were sitting around who had been in that session and other conversations over the past 3 days. I said that from my notes it looks like we have a project and asked if they were interested in carrying it out. Much interest was expressed. An Inuit woman created an Inuit steering committee, consisting of youth, elders, and community workers. I went south and created a multidisciplinary research team across several universities. We all worked together for the next 4 years developing the project. We applied for federal funding and received it from Health Canada, and began our first PAR study.

I worked closely with the youth committees in two communities that were suggested by the Inuit steering committee, one with a very high suicide rate and the other with a low rate. By the time we started the study, the suicide rates had reversed themselves. The youth committees helped design the questions we were going to use in the interviews. In one community, the youth committee suggested that we put together the questions in a survey and give it to students in the schools, suggesting that we may involve more youth this way if some did not want to be interviewed. We did this and received more responses. We interviewed about 100 Inuit in two communities between the ages of 14 and 94 years. The questions were based on Inuit suggestions during the conference. The interviewers included, along with me, a graduate student and two Inuit of whom one was on the steering committee. We had two respected elders test the interview as participants, and they approved it. We spent 2 months in the winter conducting the interviews. We found that family was the most important factor in well-being, followed by

talking/communication and following cultural values and practices. Unhappiness was the absence of these. We learned a lot about suicide and suicide prevention from Inuit. Most important was that they be in charge of suicide prevention. Dissemination took place in the communities and in publications (Kral & Idlout, 2009; Kral, Idlout, Minore, Dyck & Kirmayer, 2011b; Kral, Idlout, Minore, Dyck & Kirmayer, 2014).

When we were finished, the local community steering committee, with the youth committee president, met with the Inuit Steering committee to review the findings. The youth committee president returned to his community and re-organized his youth committee. They decided that for suicide prevention they would develop a youth center. With the help of a local film company, Isuma, they were able to open the center. The center had games, a pool table, a large screen for movie nights, and elders coming in to teach youth about their culture. The youth committee also put together a peer counseling group, who were able to speak with troubled youth in the community. After 2 years, there were no suicides, and the community celebrated this. Unfortunately, the funding ran out and the youth center was closed. Soon the suicides returned at a high rate.

Eight years later, I returned to the community for a year of ethnographic research for my anthropology dissertation, as I am interested in culture and community psychology (Kral et al., 2011a,b). I began working with the next generation of youth committee members. Their primary goal was to re-open the youth center. This committee met weekly in the house I was living in, so I was active in their work or, at least active on the side. With another Inuk (singular for Inuit), we organized the youth in the community to come together to talk about what they would like to see in the youth center. I discovered grants they would be able to apply for, and most of them concerned Indigenous culture. So we gathered a large group of youth and asked them for their suggestions. I told them about the grants, and they were enthusiastic to give ideas that related to their culture for the youth center. They delivered 26 solid suggestions. With the youth committee, we organized these 26 ideas into three themes for which we wrote territorial and federal grant applications. Fortunately, they received the grants and were able to re-open the center. On opening day the community again celebrated, with many Inuit coming out to the event. The youth committee members were on the roof of the center tossing candy down to the children who were there. It was a very happy occasion. Eight years after the re-opening of the center, compared to the 8 years prior, suicides decreased by 68% (Kral, 2012).

In another PAR study, a group of us decided to study resilience among Indigenous Arctic youth. Across five



universities, researchers decided to invite five communities in Siberia, Alaska, Nunavut, and Norway where we had been conducting research for many years. We organized a steering committee in each community, and I returned to the main community I had been working and living in Nunavut. We applied for research funding with the National Science Foundation, who generously funded us. We had a meeting with one adult and two youth from each steering committee and the researchers at the University of Cambridge, one of the participating universities. Two of the academic researchers were Indigenous from their participating community. In Cambridge, the meeting was started by the youth, who I suggested should meet before the big meeting to discuss what the research questions would be. When our meeting began, and the meeting lasted several days, the youth told us what they had talked about and what they wanted to study. From there, we put together a research plan. Each of the researchers worked with their respective community and steering committee. Over the next year, we met often via phone conferences to put together the interview. Then, the academic researchers went to the communities to work with the steering committees and interview youth. We interviewed about 20 youth in each community. After the interviews were done, the researchers met to put together a coding scheme for the interviews. Our findings showed resilience to be not a personality variable but an ecological, social matter. Resilience was social, based on youth speaking with friends and family members about their problems. With family being seen as very important, the steering committee in my community began organizing family activities. And we published a paper (Kral et al., 2014).

As indicated earlier in this paper, our PAR has been an attitude rather than a specific research method. Relationships have been formed with the communities that are respectful, mutual, and sharing with a deep collaboration taking place (Kral & Allen, 2016). Community covenantal ethics are important, which include reciprocal responsibility, collaborative decision-making, and power sharing (Brydon-Miller, Kral, Maguire, Noffke & Sabhlok, 2011). Our work with Indigenous communities comes from not only PAR, but an acknowledgment that Indigenous peoples are in a movement of self-determination, reclaiming the power over their lives that had been taken away from them (Kirmayer, Gone & Moses, 2014). The PAR in the communities, even the youth center, is what I call sovereignty on the ground. These activities are linked to larger Indigenous movements such as self-government (Niezen, 2003). Since 1999, Nunavut has been a political territory, and the government leaders are Inuit. Indigenous self-determination is a difficult process and often does not produce the desired results (Keal, 2007). Nonetheless, Indigenous communities developing their own programs

is an approach that aligns well with PAR. As Appadurai (2004) argues, is work that has the capacity to aspire and empowers communities to own and run projects. We have found that community collective efficacy produces programs that work. Traditional, Western community mental health services do not always fit culturally with Indigenous peoples. Our work with Inuit also fits with the values of community psychology regarding social justice, helping minority populations, participation, and community action.

## Conclusion

Through these case studies, we have attempted to illustrate how participatory, action-oriented approaches to research have woven their way through our careers as academics working in community mental health. For all of us, PAR has been fundamentally a process of lifelong learning and unlearning—learning from our many partners over the years the right questions, the right language and, while enabling inquiry and action, just as importantly, unlearning beliefs and ways of partnering that impede participatory engagement. Building from the fundamental social justice agenda of PAR (Fals Borda, 1991; Fals Borda, 2008; Torre & Ayala, 2009), we believe that our efforts are illustrative of efforts to apply these methods in the contemporary frame. Such efforts include a flexible application to suit the lived realities of individuals such as homeless youth with highly unstable life circumstances, the creation of multiple avenues for engagement depending on life circumstance and identity (e.g., Indigenous Elders and youth), and weaving PAR principles into long-standing programs of work that increasingly connect with mental health reform and evolving health care policy (e.g., “stakeholder involvement”).

We are in an interesting time in the field of participatory engagement in community psychology and community mental health. There are increasingly informed and empowered communities seeking justice—communities that do not require conscientization or outsider help to achieve and maintain it. We also have more receptive policy and service audiences that are frequently deploying concepts such as community inclusion and patient engagement (Kidd et al., 2014). While these are promising developments, efforts that are labeled participatory face similar challenges as work labeled “recovery-oriented.” More specifically, true PAR-driven change is readily obscured by superficial endeavors labeled with PAR-related terms. For example, when PAR is described and applied in superficial, “project”-oriented ways, there is a risk that mainstream establishments will fund small, unsustainable examples of such work to provide appealing optics.

Meanwhile, the fundamental structures that propagate exclusion and inequity will remain untouched. Another interesting question is, as communities become more empowered and drive more of the research process, can this research in turn drift away from PAR methods? Indeed, ownership of the research agenda is but one aspect of PAR and there is a risk in assuming that just because a marginalized group is leading the research endeavor that rigor regarding equity, reflexivity, and social action will automatically follow. Finally, bias against PAR as a legitimate method continues to be expressed through rejected grant proposals, challenged academic promotions, and publications relegated to niche journals.

Coming back to Fals Borda's emphasis that PAR is about social, political, and cultural change and struggle (Fals Borda, 2008), we conclude by suggesting that PAR offers a very important tool in the struggle to address the inertia in the field of community mental health upon which this special issue is focused. Clinical trials and biologic psychiatry cannot address systemic inequities and wicked problems—politically oriented movements and grassroots advocacy can, however. PAR and efforts like it can create the fundamental change that, coupled with emerging methods from other fields that better address complex systems (e.g., public health; Luke & Stamatakis, 2012), hold great promise in addressing the appalling health disparities experienced by people with severe mental illness (Hayes et al., 2017; Olfson et al., 2015). Herein, we hope to have provided some lessons learned over our careers that might inform a renewed effort by community psychologists to challenge and re-engage our current services and systems that are so ill-equipped to address community mental health.

## Conflicts of interest

We have no conflicts of interest to disclose. The work described in this manuscript complies with ethical standards.

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