"Nothing about me, without me": Participatory action research with self-help...
Geoggrey Nelson; Joanna Ochocka Kara Griffin; John Lord
American Journal of Community Psychology; Dec 1998; 26, 6; ProQuest Psychology Journals
pg. 881

American Journal of Community Psychology, Vol. 26, No. 6, 1998

"Nothing About Me, Without Me": Participatory Action Research with Self-Help/Mutual Aid Organizations for Psychiatric Consumer/Survivors[1]

Geoffrey Nelson[2]
Wilfrid Laurier University

Joanna Ochocka
Centre for Research and Education in Human Services, Kitchener, Ontario

Kara Griffin
Wilfrid Laurier University

John Lord
Ryerson Polytechnic University

Participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors is reviewed. We begin by tracing the origins of and defining both participatory action research and self-help/mutual aid. In so doing, the degree of correspondence between the assumptions/values of participatory action research and those of self-help/mutual aid for psychiatric consumer/survivors is examined. We argue that participatory action research and self-help/mutual aid share four values in common: (a) empowerment, (b) supportive relationships, (c) social change, and (d) learning as an ongoing process. Next, selected examples of participatory action research with psychiatric consumer/survivor-controlled self-help/mutual aid organizations which illustrate these shared values are provided. We conclude with recommendations of how the key values can be promoted in both the methodological and sub-

[1]An earlier version of this paper was presented at the Self-Help Research Pre-Conference, Society for Community Research and Action Biennial Conference, May 28, 1997. Thanks to Kathryn Church, Isaac Prilleltensky, and Marnie Shepherd for their comments on the earlier version.
[2]Address all correspondence to Geoffrey Nelson, Department of Psychology, Wilfrid Laurier University, Waterloo, Ontario, Canada N2L 3C5; e-mail: gnelson@mach1.wlu.ca

0091-0562/98/1200-0881$15.00/0 © 1998 Plenum Publishing Corporation

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

stantive aspects of future participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors.

KEY WORDS: participatory action research; self-help/mutual aid; mental health; psychiatric consumer/survivors.

Participation in self-help/mutual aid groups has been rising over the past three decades (Kessler, Mickelson, & Zhao, 1997). In particular, self-help/mutual aid organizations operated by and for people with serious mental health problems have expanded. For example, in our home province of Ontario, Weitz (1984) identified four consumer/survivor-controlled organizations, not including branches of Recovery, Inc., in 1984, but by 1998, this number had grown to more than 50 publicly funded consumer/survivor initiatives (Shepherd, 1998, personal communication). Similarly in the U. S., Zimmerman *et al.* (1991) reported that GROW, a self-help/mutual aid organization for users of mental health services, grew from no groups to nearly 100 groups in the state of Illinois over a period of 7 years.

As these self-help/mutual aid organizations have become more prominent, there have been increasing calls to examine the nature and effects of these diverse organizations and to determine what relationship they have and should have with mainstream, public mental health services. Trainor, Shepherd, Boydell, Leff, and Crawford (1997) have conducted an evaluation of 14 of these organizations in Ontario. In the U. S., there are two centers for self-help research and knowledge dissemination that have been funded by the National Institute of Mental Health, one at the University of Michigan (Thomas Powell, Principal Investigator) and one at the University of California, Berkeley (Steven Segal, Principal Investigator) (Powell & Cameron, 1991; Segal, Silverman, & Temkin, 1995). Also, Julian Rappaport, Edward Seidman, and their research team from the University of Illinois at Urbana–Champaign have conducted a large-scale collaborative investigation of GROW (Rappaport *et al.*, 1985). Finally, other sources indicate a rapidly growing research literature on self-help/mutual aid organizations for psychiatric consumer/survivors (see Davidson *et al.*, 1997; Humphreys, 1996). To varying degrees, most of these investigations have used participatory and/or action-oriented research methods.

In view of this growth, it is important to reflect on what we have learned to date and to consider directions for future research in this area. To this end, this paper has three objectives: (a) to examine the degree of correspondence between the assumptions/values of participatory action research and those of self-help/mutual aid for psychiatric consumer/survivors, (b) to review examples of participatory action research with psychiatric consumer/survivor-controlled self-help/mutual aid organizations which illus-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

trate the values that are shared between the two, and (c) to make recommendations of how the values can be promoted in both the methodological and substantive aspects of future participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors. We rely both on our own experiences and those of others who have conducted participatory action research with self-help/mutual aid organizations for consumer/survivors.

Before beginning, we note that we use the term "psychiatric consumer/survivor" to refer to people who have been diagnosed with and often hospitalized for serious mental health problems, such as schizophrenia, unipolar depression, and bipolar disorder, and who participate in self-help/mutual aid organizations. We use the term "consumer/survivor," rather than professional language such as "patient," "client," or specific diagnostic labels, because that is the term that people who participate in self-help/mutual aid organizations use to describe themselves, particularly in our home province of Ontario (Burstow & Weitz, 1988; Capponi, 1992; Chamberlin & Rogers, 1990). Although the terms "consumer" and "survivor" have been assailed by some professionals (Torrey, 1997), we believe that people have the right to define themselves in whatever terms they choose. We also recognize that not everyone prefers the term "consumer/survivor."

PARTICIPATORY ACTION RESEARCH AND SELF-HELP/MUTUAL AID ORGANIZATIONS FOR PSYCHIATRIC CONSUMER/SURVIVORS: COMMON VALUES

Research methods, such as participatory action research, and methods of action, such as self-help/mutual aid organizations, are based on underlying assumptions/values that are very consistent with the values of community psychology (Prilleltensky & Nelson, 1997). It is these assumptions/values, either implicit or explicit, which are the defining characteristics of the world view of a research or action approach. Like others (Borkman & Schubert, 1994; Chesler, 1991; Kennedy, Humphreys, & Borkman, 1994; Lavoie, 1984), we argue that the assumptions/values underlying participatory action research and self-help/mutual aid organizations are quite compatible, and thus that participatory action research is a good fit for the study of self-help/mutual aid organizations for psychiatric consumer/survivors. Both participatory action research and self-help/mutual aid organizations represent alternatives to conventional research and intervention.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Participatory Action Research

Participatory action research is a form of applied research that represents a fundamentally different paradigm than conventional research (Chesler, 1991; Lincoln & Guba, 1985). Participatory action research blends the traditions of participatory research and action research. Participatory research emerged from work with oppressed peoples in developing countries (see Yeich, 1996). For example, Freire (1970) and his colleagues from Latin America developed the widely influential concept of adult education, engaging individuals in critical analysis and organized actions to improve their situations. Participatory research works on the assumption that oppressed people themselves are fully engaged in the process of investigation. They participate in a process of developing research questions, designing research instruments, collecting information, and reflecting on the data in order to transform their understanding about the nature of the problem under investigation. With its connections to social movements, participatory research has been defined (Hall, 1993): "as a way for researchers and oppressed people to join in solidarity to take collective action, both short and long term, for radical social change" (p. xiv).

Action research was introduced in North America over 50 years ago by Lewin (1946), who suggested that the best way to learn about social systems was to try to change them. Lewin proposed cycles of problem definition, fact finding, goal setting, action, and evaluation to simultaneously solve problems and generate new knowledge. Thus, one important characteristic of action research is to organize the research into different phases, with findings informing action throughout the process. Also, action research identifies and involves key stakeholders at all stages of planning and implementation. Closely associated with organization development, action research has traditionally worked with human service staff and managers, but less often with service users.

Although participatory research and action research share some common assumptions, they differ in some respects (Brown & Tandon, 1983; Reason, 1994). Participatory research has focused on power differences and class conflicts and has been associated with grass-roots movements for social change, whereas action research has tended to minimize power differences and conflict and to be allied with those in power in organizations (Brown & Tandon, 1983). Indeed, the issue of power and the challenging of authority is central to this discussion as a distinguishing feature of the two approaches. While action research works from a standpoint of agreement and consensus, participatory research recognizes the challenges inherent in doing work where the powerful in society may resist when they feel their power threatened (Borkman & Schubert, 1994; Yeich & Levine,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

1992). As Borkman and Schubert (1994) suggested, "there still seems to be little communication between the two traditions" (p. 50).

In much of our work, we combine the principles of these two traditions. From participatory research, we recognize power imbalances and the need to engage oppressed people as agents of their own change. From action research, we recognize the value of engaging other stakeholders and of using research findings to inform intervention decisions. Thus, we define participatory action research as *a research approach that consists of the maximum participation of stakeholders, those whose lives are affected by the problem under study, in the systematic collection and analysis of information for the purpose of taking action and making change*. Throughout the remainder of the paper, we use the term "participatory action research" defined above.

Participatory action research involves a high degree of cooperation between researchers and stakeholders with constant feedback loops and a commitment to using the findings and to raising all participants' consciousness about the problem in its social context (Barnsley & Ellis, 1992; Chesler, 1991; Gaventa, 1993). The desired process of participatory action research is one that is: democratic (enabling the participation of stakeholders), equitable (acknowledging people's equality of worth), liberating (providing freedom from oppressive conditions), and life enhancing (enabling the expression of people's full human potential) (Stringer, 1996).

In the remainder of this section, we outline what we believe to be the main assumptions/values that underlie participatory action research. The values we describe are ones that are important to us and have informed our work and thinking about research and action (Lord & Hutchison, 1993; Prilleltensky & Nelson, 1997). We believe the power of values lies in their capacity to ground us in a set of beliefs that are conscious and that direct our actions. Although these values help us to be coherent in our thinking and to guide our actions, learning to live our values is an ongoing challenge.

Empowerment

Many researchers emphasize that a major goal of participatory action research is to help empower those with little or no power to control their lives, or to amplify their "voices" and expand their "choices" (Park, Brydon-Miller, Hall, & Jackson, 1993; Ristock & Pennell, 1996). Participatory research "fundamentally is about the right to speak" (Hall, 1993, p. xvii) and strives to enhance both psychological and political power (Park, 1993). These notions are congruent with our definition of participatory action research. As Whitmore (1991) stated:

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> Empowering the less powerful people in a society is thus a major, explicitly-stated goal of participatory researchers and evaluators. In conducting an inquiry, they assume that knowledge is a source of power and that community people—not only the officially identified experts—can generate important and valid knowledge. Science is seen as a political and cultural product, not as a neutral activity. (p. 2)

Stakeholders act as both participants and coresearchers in the research process (Argyris & Schön, 1984). As Gaventa (1993) suggested, participatory research "attempts to break down the distinction between the researchers and researched, the subjects and objects of knowledge production, by the participation of the people-for-themselves in the process of gaining and creating knowledge" (p. 34). Control and ownership over the research process and research findings is shared among all participants. We have found that this is difficult in practice because it involves a shift in roles for both the researchers and the participants. The dilemma is two-sided: researchers need to "let go" of control, and consumer/survivors need to "step up" and become more engaged. Since both partners are steeped in the positivist paradigm, it often takes time to make these role shifts. Stringer (1996) summarized the main characteristics of participatory action research: choice, participation, inclusion, and communication. The characteristics of choice and participation reflect the value of empowerment, whereas inclusion and communication reflect the importance of supportive relationships, which is the next value to be discussed.

Supportive Relationships

As stated above, we believe that one of the most important features of new paradigm research is illustrated by the types of relationships that may exist between researchers and participants (or coresearchers) (Smith, 1994). In particular, participatory action research involves relationship building and may foster a connectedness not only to the topic area, but often to the people involved. In some participatory action research studies, the researcher facilitates a process of building a partnership among professionals, family members, consumer/survivors, and other stakeholders. In other studies, consumer/survivors are the prime stakeholders. Stakeholders collaborating with researchers work to develop egalitarian and authentic relationships and trust. By collaborating and sharing stakeholders' diverse knowledge and experience, participatory action research seeks to change the social and personal dynamics of the research situation so that it is cooperative and enhances the lives of all those who participate (Stringer, 1996). We believe that clear communication and a conscious deemphasis on professional jargon are important in participatory action research.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Being reflexive or having an "equal engagement" in research activities with the people requires that research be carried out and conceptualized in new ways (Smith, 1994). Indeed, bringing parts of oneself as researcher and participant is a quality of participatory action research. For us, this has meant that both our private and public selves are merged more fully in the research context. From our experiences in working with psychiatric consumer/survivors, we cannot overestimate the importance of relationship and concern with research participants. Within this framework, we have found that dialogue is a distinguishing feature of participatory action research in which people unite, perhaps similar to self-help/mutual aid groups, to share common experiences, and speak in a "full voice" (Park, 1993). The importance of dialogue is captured well in the following quotation from Park (1993).

> Through dialogue people come together and participate in all crucial aspects of investigation and collective action . . . . Problems facing the poor and the powerless must be understood in the hearts and the guts as well as in the heads, and the people with the problems must talk to each other as whole persons with feelings and commitment as well as facts. As a tool of research, dialogue produces not just factual knowledge but also interpersonal and critical knowledge, which defines humans as autonomous social beings. (p. 12)

In participatory action research, people become participants in ways that most other research approaches do not allow, and subsequently, gain a greater knowledge about themselves, their lives, and their communities (Park, 1993). As Stringer (1996) has stated, participatory action research can be characterized as "the search for understanding in the company of friends" (p. 160). These supportive working relationships enable people to share honestly, which includes respectful disagreement and discussion.

Social Change

Participatory action research focuses on useful knowledge, problem solving, and social change. It strives to integrate research and intervention so as to reduce the gap between knowledge and action. Participatory research emphasizes "mobilizing oppressed people to create societal-level change" (Yeich & Levine, 1992, p.1899). "Defining their own reality" heightens consciousness, and participants may then begin to challenge expert or dominant ideas and empowerment is fostered (Gaventa, 1993). As Kroeker (1996) stated:

> It (participatory action research) is premised on the belief that linking research to action is crucial . . . Action . . . is carried out through equal participation. Action is collectively constructed, just as research. Action is intrinsically tied to research, because

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> activism without analysis is counterproductive and potentially detrimental. An "action-reflection-action" cycle provides the most potential for empowerment. (p. 136)

Examples of social change resulting from participatory action research include the enhancement of a community economic development organization for people of low income, immigrants, and refugees in a Canadian city (Papineau & Kiely, 1996), the creation of an organization of homeless people in the U. S. to lobby for affordable housing (Yeich, 1996), and the development of citizen participation in the cooperative movement in Nicaragua (Kroeker, 1996). In our own work, with other stakeholders, we contributed to the development of a provincial Support Clusters Network for people with disabilities and their families (Ochocka, Roth, Lord, & MacNaughton, 1993).

Learning as an Ongoing Process

Participatory action research focuses on being responsive to participants' needs and perspectives, collective consciousness-raising about the issues under study, and continuous innovation and renewal. One goal of participatory action research is to understand and magnify how participants' perceptions and realities are constructed and how such constructions can build and change social interventions. Rather than focusing on replication, learning should be maximized through a focus on innovation. All of this involves a willingness and commitment to "learning as we go" (Ochocka *et al.*, 1993).

Whereas traditional research tends to be deductive in its emphasis on hypothesis testing, participatory action research tends to be inductive. Findings emerge during the research process and theory is grounded in the emerging findings (Chesler, 1991). This value was a prominent feature in the work of our colleague, Kathryn Church (Church & Creal, 1995a, 1995b), with psychiatric consumer/survivors engaged in community economic development. Participants learned by doing in such a way that they were not restricted or confined by expertise, but, as Church noted, made mistakes and took risks. In her words, which are appropriate for both participatory action research and self-help/mutual aid, they "failed forward" (Church, 1997).

Self-Help/Mutual Aid Organizations for Psychiatric Consumer/Survivors

As Humphreys and Rappaport (1994) have argued, self-help/mutual aid represents a fundamentally different world view or paradigm than professional services. Several writers (e.g., Borkman, 1990; Rappaport, 1993)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

have noted the differences between professional help and self-help. We define self-help/mutual aid organizations as *settings in which people with a problem in living or a common experience come together on a voluntary and equal basis to share their experiential knowledge and to provide and receive informal social support.*

Many self-help/mutual aid organizations for psychiatric consumer/survivors were born out of negative experiences with professionals and the formal mental health system. In Canada, for example, Chamberlin (1987), a psychiatric survivor, wrote about her experiences in a book entitled *On Our Own: Patient-Controlled Alternatives to the Mental Health System.* Inspired by her work, a group of survivors in Toronto developed a self-help/mutual aid organization and named it after the title of Chamberlin's book. On Our Own developed a business, the Mad Market, and operated a successful magazine, Phoenix Rising, for many years (Weitz, 1984). Survivors have gone public and told stories of the abusive and paternalistic treatment that they have experienced at the hands of the mental health system (Burstow & Weitz, 1988). Several writers have traced the origins and growth of the psychiatric survivor liberation movement (Chamberlin, 1990; Church, 1993; Everett, 1994). The more radical survivor organizations reject the medical model and the notion that the mental health system has a benevolent focus on "treatment." Rather, they view the mental health system as an agent of social control and oppression, which strips people of their rights (e.g., involuntary hospitalization) and subjects people to demeaning treatments and abuse (e.g., ECT) (Burstow & Weitz, 1988).

We suggest that self-help/mutual aid organizations share four values in common with participatory action research, which we described in the previous section. It is important to recognize that there is considerable diversity within self-help/mutual aid organizations with respect to these values. One value may be more central to an organization than others at any given point. Also, some organizations will manifest certain values more fully than other organizations.

Empowerment

Psychiatric survivor Don Weitz (1984) spoke of the "power reversal" that occurs in self-help/mutual aid organizations. Whereas relationships between consumer/survivors and professionals are characterized by a power imbalance, in self-help/mutual aid organizations members share power. Professional expertise is demystified in self-help/mutual aid organizations, and people who have experienced mental health problems are seen as having valuable experiential knowledge which can be shared with others in a proc-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

ess of mutual aid (Trainor, Pomeroy, & Pape, 1993). The notion of survivor "voice and choice" refers to the importance of self-determination and participation in consumer/survivor-controlled organizations (Nelson, Walsh-Bowers, & Hall, 1998). Empowerment also means focusing on people's strengths and abilities, not deficits (Saleeby, 1992).

Rappaport (1987) presented empowerment as a multilevel construct. In this regard, Segal *et al.* (1995) also suggested that empowerment in self-help/mutual aid organizations for psychiatric consumer/survivors can be conceptualized as occurring at three interrelated levels: (a) personal empowerment, which includes a psychological sense of control and actual experiences of control, (b) organizational empowerment, which increases the self-determination and participation of those within the organization, and (c) community empowerment, which consists of participation in community and political change activities.

Supportive Relationships

The second value, supportive relationships, refers to peer support and what Sarason (1988) has called a "psychological sense of community." The mental health system tends to surround people with serious mental health problems with a sea of professionally delivered services, to use McKnight's (1995) language, which stigmatize them and set them apart from the community. In contrast, in self-help/mutual aid organizations for psychiatric consumer/survivors, members become a valued part of community, and there is a focus on the whole person, including his or her strengths and potential for contribution to the community. Levine and Perkins (1997) have analyzed the concept of social support in the context of self-help/mutual aid organizations and have argued that there are several key features to this concept:

> Self-help groups: (a) promote the psychological sense of community; (b) provide an ideology that serves as a philosophical antidote; (c) provide an opportunity for confession, catharsis, and mutual criticism; (d) provide role models; (e) teach effective coping strategies for day-to-day problems; and (f) provide a network of relationships. (p. 313)

Social Change

Self-help/mutual aid organizations for psychiatric consumer/survivors are quite diverse with respect to their politics and orientation towards social change. Some, like Recovery, Inc. (Raiff, 1984), hold positive attitudes towards and work in collaboration with mental health profes-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

sionals. Nevertheless, the mere presence of self-help/mutual aid organizations, no matter how politically conservative, suggests some dissatisfaction with the status quo of exclusively professional services and thus an implicit espousal of the need for alternative approaches. At the other end of the political spectrum, some survivor organizations view the mental health system from a sociopolitical framework and have an explicit antipsychiatry orientation (Burstow & Weitz, 1988). Radical self-help/mutual aid organizations seek to change the oppressive social conditions (e.g., poverty, loss of civil liberties, abuse, poor housing, stigma) which many consumer/survivors face. Chamberlin (1978) has identified these two self-help approaches as (a) partnership approaches with professionals and (b) separatist approaches, from which professionals are excluded. Consistent with this distinction, Emerick's (1990) survey of over 100 self-help/mutual aid organizations for psychiatric consumer/survivors showed that the majority of these organizations could be characterized as social movement groups with a focus on political activism, while the remainder focused more on social support for members. Thus, some groups may place more value on social change, while others place more value on the development of socially supportive relationships.

However, our experience suggests that this distinction is not always so clear-cut. We are aware of and have worked with some organizations that strive to create change within a partnership approach with other mainstream organizations as well as to provide peer support. Our observation is that partnership approaches can be used to work from within the mental health system to make change, while separatist approaches work outside the system to make change. Examples of partnership approaches include coalitions between consumer/survivors, professionals, and other stakeholders to lobby for supportive housing (Nelson, 1994) and changes in mental health legislation (Church, 1996). An example of a separatist approach is the survivor movement to ban the use of ECT (Hooper, 1987).

Social change can be aimed at several different levels of analysis, including organization, community, and social policy. Organizational change might focus on changing mental health services to make them more responsive to consumer/survivors' needs (Nelson, Lord, & Ochocka, 1996). Changes at the community and social policy level often focus on increasing consumer/survivors' access to valued resources, including housing, income, employment, and education (Nelson *et al.*, 1998). Supported housing, employment, and education and consumer/survivor-run businesses and housing cooperatives are alternatives which can increase consumer/survivors' access to such basic resources (Carling, 1995; Church & Reville, 1989; Trainor & Tremblay, 1992).

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Learning as an Ongoing Process

Many self-help/mutual aid organizations for psychiatric consumer/survivors have a focus on learning as an ongoing process, which is consistent with Senge and colleagues' notion of a "learning organization" (Senge, 1990b; Kofman & Senge, 1993). Learning organizations are committed to "a new way of thinking, feeling, and being," or a culture of learning, change, growth, and community building (Kofman & Senge, 1993, p. 6). "The impulse to learn, at its heart, is an impulse to be generative, to expand our capability" (Senge, 1990a, p. 8). In a learning organization, there is an assumption that everyone has the capacity to learn and grow. Also, learning occurs at all levels of the organization, including the individual, team or group, and the organization. Moreover, learning occurs in context and is both reflective and action-oriented.

The membership of learning organizations is encouraged to develop a vision of where they want to be. The creative tension between the vision and current reality is what motivates learning and change. The struggle to actualize the vision and values of the learning organization in the context of current realities guides the organization as a whole and the day-to-day actions of members. Developing and striving to implement the values often leads to a questioning of assumptions about traditional ways of thinking and behaving, which takes members beyond their zones of comfort. Through dialogue, support, and personal reflection, members generate innovative practices. Finally, learning organizations never "rest on their laurels," as the values and realities of the organization are constantly changing. Thus, learning is an ongoing process.

Rappaport (1993) has suggested that self-help/mutual aid organizations have their own world views and a community narrative which expresses that view. He asserts that the stories of individual members show a shift over time as they adopt the community narrative as their own. Kennedy and Humphreys (1994) have provided some support for this assertion in studies of AA and GROW, both of which use a 12-step approach to change and emphasize the role of a higher power. They found transformations in four domains of the world views of group members: (a) the self, (b) relationships with others, (c) the universal order, and (d) the nature of the problem or affliction. These findings are consistent with a central theme of the learning organization, namely, that there is constant striving to actualize the values and vision of the organization. At this point, we know less about how self-help/mutual aid organizations, as a whole, learn and grow.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table I. Assumptions/Values Underlying Participatory Action Research and Self-Help/Mutual Aid Organizations for Psychiatric Consumer/Survivors

Empowerment	Power sharing	Power reversal
	Voice and choice	Voice and choice
	Participation	Participation
Supportive relationships	Connectedness	Peer support
	Cooperation	Opportunity to provide support
	Communication	Sense of community
Social change	Useful knowledge	Political analysis
	Problem-solving	Strategies and levels of change
	Social action	Access to valued resources
Learning as an ongoing process	Sharing perspectives	Culture of learning
	Collective consciousness-raising	Learning in context
	Continuous innovation	Learning, action, and change

Summary

Our review of participatory action research and self-help/mutual aid organizations for psychiatric consumer/survivors suggests that there is compatibility in the assumptions/values which underlie these approaches to research and action. In Table I, we outline these common assumptions/values and illustrate how they are manifested in each approach. Similarly, Kennedy *et al.* (1994) have argued that the naturalistic paradigm is a better fit for research with self-help/mutual aid organizations for consumer/survivors than the positivist paradigm. As well, Rogers and Palmer-Erbs (1994) have suggested that participatory action research can be fruitfully used in the entire field of psychiatric rehabilitation.

SELECTED EXAMPLES OF PARTICIPATORY ACTION RESEARCH WITH SELF-HELP/MUTUAL AID ORGANIZATIONS FOR PSYCHIATRIC CONSUMER/SURVIVORS

In this section, we provide the reader with selected examples of participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors. Our aim is not to be comprehensive but rather to give the reader a flavor of research with self-help/mutual aid organizations that illustrates the four values we have outlined. Although the examples that follow may pertain to more than one value, the examples that we have selected fit best with the particular theme they were chosen to illustrate. In each part, we also identify dilemmas associated with the implementation of this approach.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Empowerment

Participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors can be conducted by consumer/survivors themselves, as is exemplified in a recent study by Chamberlin, Rogers, and Ellison (1996). The authors engaged 10 individuals as an advisory board to design and direct a survey of the characteristics of members of 271 self-help/mutual aid organizations. Moreover, this board brainstormed a definition of consumer/survivor empowerment and used this definition to guide the development of a questionnaire to assess personal empowerment for the survey (Rogers, Chamberlin, Ellison, & Crean, 1997).

Partnership approaches can also be employed with professionals and members of the self-help/mutual aid organization. In our research work with consumer/survivors, which has spanned a 10-year period, we have shifted towards a more participatory approach. Our notions of what it means to be a good researcher have changed from an emphasis on expertise in research design and measurement to more of an emphasis on the interpersonal and political dynamics of the research process. This shift has not been an easy one. Through many years of socialization, both edicts of "control" and the notion that we as researchers are in sole possession of "knowledge and truth" were drummed into us. However, as we have given up control over the research process, we have developed more reciprocal relationships with consumer/survivors, which has been personally engaging and rewarding and which has helped us to connect many different aspects of ourselves (personal, professional, and political). We have found that the challenge of this work involves both "working across differences" and finding common ground (Church, 1994).

A recent example of our work is a study of the changing relationships between self-help group members and professionals. We worked with a steering committee, which included members of two consumer/survivor self-help/mutual aid organizations and professionals from two community mental health organizations (Constantino & Nelson, 1995). This group formulated the purpose of the study and research questions, decided on research methods, recruited members of their organizations to participate in the research, interpreted the findings, and suggested how the findings could be used to promote change. This reflects the value of empowerment in that consumer/survivors participated with the researchers and had control over the nature of the research design and process.

These examples illustrate how the value of empowerment can be implemented in the process of participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors. In these two studies, consumer/survivors actively participated in and exerted control over

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

many aspects of the research *process*. We need to be aware that we as researchers are the guests and self-help/mutual aid organizations are the hosts of the research, as Rappaport *et al.* (1985) have noted. Research with self-help/mutual aid organizations for psychiatric consumer/survivors can also focus on empowerment in the *content* of the research. For example, Segal *et al.* (1995) developed measures of personal, organizational, and community empowerment in a study of four self-help/mutual aid organizations for psychiatric consumer/survivors and found that these measures were related to a number of positive outcomes.

Supportive Relationships

The development of supportive relationships has also been a focus of both the content and the process of participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors. Contrary to conventional inquiry that promotes separation from those participating in the research, Rappaport *et al.* (1985) utilized a research methodology, in their evaluation of GROW, that fostered relationships with their participants. The authors contend: "The participant observers are selected not only on the basis of their data collection skills, but also on the basis of their ability to form genuine relationships with members and their willingness to respect the GROW approach" (p. 16). Researchers interact with members on a regular basis and "come to be seen by members as genuine and concerned people, not mysterious or imposing figures" (p. 16). The researchers also focused on the *content* of supportive relationships within GROW meetings, using systematic observations of over 500 meetings of 15 different GROW groups. Roberts *et al.* (1991) found, among other things, that over time GROW members showed increases in several different supportive behaviors directed to others in the group.

In the study mentioned earlier (Constantino & Nelson, 1995), we focused on both the process and the content of supportive relationships between self-help/mutual aid groups for consumer/survivors and mental health professionals. The steering committee, comprising consumer/survivors, professionals, and researchers, designed a study of how current relationships between consumer/survivors and professionals could be improved. Participants suggested specific ways in which professional ideology and power needed to be changed. Bringing these two groups together to conduct such a study was part of a broader process which has led to changes in the relationships between consumer/survivors and professionals in our community.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Social Change

An excellent example of action-oriented research with self-help/mutual aid organizations for psychiatric consumer/survivors that focuses on social change is the work of Church (1993, 1995, 1996), who studied consumer/survivor participation in formulating community mental health legislation in Ontario. Church was hired by a group called Toronto Psychiatric Survivors to study consumer/survivor participation in the public hearings held by a provincial mental health legislation subcommittee. Using qualitative methods (field notes and interviews), Church documented the impact that consumer/survivors who sat on the committee and consumer/survivors who made presentations to the committee had on the process and outcome of this committee.

The painful stories told by consumer/survivors were "unsettling" for the professionals who participated in this exercise, and consumer/survivors' "bad manners," which included personal experiences and emotions as forms of knowledge, challenged the taken for granted rules for "proper" participation in such a process. Consumer/survivor participation had a strong impact on the final report of the subcommittee. While the government never did enact community mental health legislation, the recommendations were quite radical in their emphasis on consumer/survivor participation, the need for housing and employment, and the funding of consumer/survivor-controlled organizations. Moreover, some of the recommendations were implemented (e.g., funding consumer/survivor-controlled organizations). Church's work provides a rich narrative of the dynamics of social change initiated by a social movement organization of psychiatric consumer/survivors.

Another example of participatory action research which focuses on social change for psychiatric consumer/survivors is Church's study of five community economic development projects in Toronto (see Church, 1997; Church & Creal, 1995a, 1995b). Church worked with the Toronto Community Economic Development Network to document the experiences of consumer/survivor-run businesses that were funded by the provincial government. A goal of consumer/survivor-run businesses is to increase consumer/survivors' access to the valued resources of work and income. Based on qualitative interviews and observations, Church and Creal (1995a, 1995b) developed a document and a video which highlighted both individual and organizational stories of these alternative settings. The video is an excellent educational tool for communicating findings, which relates to the next theme of the importance of learning.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Learning as an Ongoing Process

One example of participatory action research in which we used continuous learning to develop an innovative approach to family and individual support was the Support Clusters project (Ochocka *et al.*, 1993). By maintaining a commitment to "learning as we go," the project effectively made use of the evaluation and action research process. The research team shared detailed evaluation insights and data with the entire project on four separate occasions. Each time these feedback sessions led to important discussions and reflections, as well as having a direct impact on the intervention. What was important about the way this study was designed was that we organized the research into phases, with learning from one phase informing subsequent phases.

We are in the process of studying three community mental health organizations in our community, one of which is a self-help/mutual aid (Nelson *et al.*, 1996). These three organizations were selected, in part, because they are attempting to shift to a new approach to services and supports based on the concepts of empowerment and community integration. All of the organizations began the process of change by using a broad consultation process to develop a vision and values for change. The emphasis on these organizations has been on developing a culture of learning and change, which is consistent with Senge's (1990a, 1990b) notion of a "learning organization."

We are using qualitative methods to document the historical and policy context of change, the processes and outcomes of change at multiple levels of analysis, and how changes are experienced by different stakeholder groups. The study, which is guided by a steering committee with consumer/survivor, family, and staff representation from the three organizations, should provide valuable information not only to the settings but also to other mental health organizations that are attempting to shift to new ways of thinking and practicing. Not only are we learning about the organizations that we are studying, but we are constantly learning about new ways to conduct participatory action research.

Even at the beginning of the project, we never expected that consumer/survivors would be participating in *every* facet of the research, including writing up the findings. This has happened because we created a climate for a positive partnership. We ensured that consumer/survivors had time to dialogue and ask hard questions before we started the study. We worked to make sure that we were not defensive as we faced some anger about the university receiving the grant money. Furthermore, we spent a lot of time "working across differences," which included finding the best times for meetings, taking frequent breaks for smokers, hiring con-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

sumer/survivor researchers, getting to know people's stories, and ensuring that people had transportation to interviews. Through this process of sustained engagement with consumer/survivors, we learned more about ourselves, which included questioning some of our assumptions and making changes in the way we work with people. Even though we remain outsiders to the consumer/survivor culture, we have gained greater insight and compassion into the key issues of concern to consumer/survivors and more respect for their knowledge and experience (Trainor *et al.*, 1993).

RECOMMENDATIONS FOR METHODOLOGY AND SUBSTANCE IN FUTURE PARTICIPATORY ACTION RESEARCH WITH SELF-HELP/MUTUAL AID ORGANIZATIONS FOR PSYCHIATRIC CONSUMER/SURVIVORS

We have developed several recommendations for methodology and substance in participatory action research work with self-help/mutual aid organizations for psychiatric consumer/survivors.

Recommendations for Methodology

Various methods can be used to foster and promote the values of empowerment, supportive relationships, social change, and a "learning as we go" process. We have organized our recommendations according to the four values that compose the framework for this paper. The reader should note that some of the recommendations pertain to more than one value.

Empowerment

We recommend the *use of research steering committees* to promote consumer/survivor empowerment in the research process. Leff, Campbell, Gagne, and Woocher (1997) cited a slogan originating from the South African disability movement: "Nothing about me, without me." A research steering committee is one concrete vehicle for amplifying the voices of consumer/survivors and other stakeholders in the research process. Steering committees should have substantial consumer/survivor membership (the actual proportions can vary according to what other stakeholders are involved in the study) that is determined by consumer/survivors. Steering committees can help: (a) to develop other ways for more people to have input on the research (e.g., holding information sessions within settings), (b) to enhance communication, (c) to foster supportive relationships, (d) to use the re-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

search for social change, and (e) to promote an ongoing process of learning (Rapp, Shera, & Kisthardt, 1993).

Research steering committees can vary in the amount of participation and control that they have over the research. At one end of the continuum is limited participation in which stakeholders provide input, while on the other end of the continuum, stakeholders direct and shape the research. In our experience, we have found it useful to have two vehicles for consumer/survivor participation. A research steering committee functions like a board and makes all decisions about the research design and process, while a research team, which includes consumer/survivors, acts as the "doers" who conduct the research. Also, like board members, steering committee members are not paid, but research team members are paid employees of the project.

Along with other researchers (Chamberlin *et al.*, 1996; Leff *et al.*, 1997; Rapp *et al.*, 1993), we (Constantino & Nelson, 1995; Nelson *et al.*, 1996) have found that such committees play an important role in actualizing the values of participatory action research and self-help/mutual aid. One of the most effective ways to enable steering committees to "own" the research process is to develop principles (e.g., not doing any harm to anyone, clear communication, keeping conversations confidential) of how to work together and how to implement the research. The use of steering committees does not eliminate power differences between researchers and consumer/survivors, but when facilitated well, they do provide a vehicle to "work across differences" and find common ground between these two constituents.

Of course, the success of steering committees depends upon the researchers' willingness to share power with stakeholders. We have learned that having consumer/survivors chair the committee, setting a tone of informality (e.g., providing food), using plain language rather than research and professional jargon, encouraging and listening carefully to members' contributions, and negotiating difficult issues are some of the ways that we can begin to reduce the gap in power between ourselves and participants, thereby nurturing reciprocal relationships and building community. For example, in our research we experienced conflict related to the inclusion of family members in the research. It was only through identifying the different viewpoints and experiences that we were able to come to a resolution. This involved an expanded definition of family (as more than parents) and ensuring that interviewers would set limits on participants talking about personal experiences of the family member with a mental health problem (which was consistent with our previously agreed upon principle of doing no harm).

We also recommend *greater use of qualitative methods* to promote consumer/survivor empowerment. Qualitative methods provide consumer/survi-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

vors with the opportunity to speak about their own experiences relatively free from any preconceptions on the part of the researcher. Borkman and Schubert (1994) noted that within participatory action research: "everyday experience and feelings are a major source of knowledge" (p. 64). Lived experience, whose importance is recognized by many feminists, is often discounted in conventional research (Kirby & McKenna, 1989). It is, however, arguably the cornerstone of both participatory action research and self-help/mutual aid for psychiatric consumer/survivors. We believe that qualitative methods are ideally suited to help people to begin to have a voice and to "reappropriate knowledge" (Gaventa, 1993). Our research through the Centre for Research and Education in Human Services has used qualitative methods extensively both to enhance and understand consumer/survivor empowerment (Lord & Hutchison, 1993; Lord, Schnarr, & Hutchison, 1987).

Supportive Relationships

Researchers who use a participatory action research approach should encourage the *development of authentic and supportive relationships*. Authenticity involves recognizing the contributions of people, sharing power with stakeholders in the research process, and acknowledging the expertise embodied in those who live the experiences. Lincoln and Guba (1986) have suggested that authenticity should be an important criterion for community research. Concretely, we have found that being on a first-name basis (avoiding titles and labels), celebrating each others' birthdays, and sharing different parts of ourselves (rather than maintaining an aura of detached objectivity) are valuable ways of establishing supportive relationships and working across differences. The linking of private and public selves is not easy for many professionals, but it is critical if we believe that experiential knowledge is an integral part of supportive relationships.

With deepening self-disclosure, reciprocity, and trust, consumer/survivors may ask professionals and researchers to assist self-help/mutual aid organizations in different ways (e.g., consultation, support). For example, we have been asked to assist consumer/survivors in formulating community economic development initiatives, negotiating conflict with other organizations, and conducting workshops on vision and values and the role of board members. Professional researchers can be helpful, when consumer/survivors set the terms of what that help entails.

As relationships deepen and sometimes turn into friendships, we also get invitations to go for a drink after meetings and individuals sometimes seek us out for personal support. When this happens, boundaries between professionals and consumer/survivors become blurred, and we as profes-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

sionals are likely to experience some confusion, role strain, and threats to identity (Church, 1995, 1996; Curtis & Hodge, 1994; Pomeroy, Church, & Trainor, 1987). We learn that supportive relationships are not just about "accepting one another," but that there are profound differences in social class and resources that underlie such relationships. Supportive relationships are also about ensuring that disadvantaged partners can get to meetings, participate with dignity, and be accepted for behaviors and language that in the professional context might be considered rude (Church, 1996).

We believe that it is important to be aware of and acknowledge such personal discomfort, as such experiences may help to inform us about how change is made. Therefore, we recommend that *researchers write about their personal experiences in research articles* (see Patterson, 1992). For example, Church's (1995) candid writing about the "unsettling" nature of her experiences working with psychiatric consumer/survivors can serve as an example for others to follow. Another format that could be used is one in which the researchers and consumer/survivors each provide their own perspectives on the research process (Woodside & Cikalo, 1995).

There also seem to be paradoxes for consumer/survivors in these role changes. We have found that consumer/survivors may get "too comfortable" with their relationships with other stakeholders, so that they may be somewhat reluctant to speak their minds. We want to emphasize that supportive relationships are not designed to obscure consumer/survivors' anger and frustration, but to give it a safe place for expression and reflection.

Social Change

One tangible way to promote consumer/survivors' access to the valued resources of employment, income, and education, which is a key component of social change, is to *hire consumer/survivor researchers*. Hiring consumer/survivors as researchers is consistent with some of our previous statements about the importance of reducing or eliminating barriers in the production and search for knowledge and change. In our current work with one self-help/mutual aid organization, we were challenged at the first steering committee meeting regarding if and when we would be hiring consumer/survivors. Subsequently, staff of this organization helped us to advertise the position, screen applications, interview applicants, and make the final decision as to who was hired. Although we initially had some differences of opinion as to who should be hired, we eventually thought that the consumer/survivor organization should have the strongest say in the decision. The person we hired has turned out to be an excellent research assistant and a great asset to the project.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

This example shows how empowerment can be fostered and how support for others' capabilities and expertise can be provided. Yeich and Levine (1992) noted that "conducting of research provides people with research skills. Acquisition of these skills means access to 'expert' knowledge" (p. 1899). The value of hiring and training consumer/survivor researchers, both for the research and for the consumer/survivor researchers, has been noted by others as well (Morrell-Bellai & Boydell, 1994; Rapp *et al.*, 1993; Srebnick, Robinson, & Tanzman, 1990). Our experience is that ongoing training and support with consumer/survivor researchers helps to create a context for learning and personal growth.

Corrigan and Garman (1997) have pointed out that funding bodies are beginning to recognize the importance of research partnerships and participatory action research. While our experience is that this is true, we also know that such research funding is still vested in research institutes and universities, not in consumer/survivor organizations. As we mentioned previously, these funding arrangements can create some tensions about who really is in control and who benefits from the research. Thus, we believe that *new and creative solutions are needed that result in shared control of the research budget.* This might involve granting agencies providing some flexibility on which organization can hold the grant and be responsible for the budget.

Another issue regarding social change is the need to locate a group or groups to use the research findings for education and/or advocacy. Not only does this demonstrate respect for the people involved, but it further transfers ownership of the research to the people (Rapp *et al.*, 1993). In reference to Tandon's earlier work, Yeich and Levine (1992) contend that "if the movement is initiated by an outside researcher, the decision-making role of the people may be limited initially, but continually grows" (p. 1896). Steering committee members can use their organizations and networks to communicate research findings.

To illustrate this point, Nelson (1994) reported on the development of a mental health coalition of consumer/survivors, family members, and service providers that used the findings from a needs assessment to advocate for supportive housing for consumer/survivors. Moreover, with the endorsement of our project steering committee, we have used findings from our current research to advocate for community mental health programs for our region. We wrote a brief that was submitted to a government-appointed Health Services Restructuring Committee, which has a mandate to review and make recommendations for changing health services in the province. For researchers who are part of research centers or universities, this strategy of locating a group to use research for advocacy is important. Researchers who are seen as advocates often lose credibility in our culture,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

because they are not viewed as "objective scientists." The participatory action researcher is especially vulnerable to this charge.

Learning as an Ongoing Process

The use of what Lincoln and Guba (1985) have referred to as an emergent (or flexible) research design is consistent with the value of learning as an ongoing process. We believe that this approach, in particular, allows those involved in the process to learn as they go, being open to changes and evolving ideas. Often we have used an emergent design in which the research is conducted in different phases, with the findings from one phase informing the design of subsequent phases (e.g., Lord & Ochocka, 1995; Nelson *et al.*, 1996). This approach stands in contrast to conventional research in which all decisions regarding the design of the study are made in advance of the data collection.

Employing an emergent design and a steering committee can help to *provide an educational component* to one's research, which encourages mutual education between researchers and participants (or coresearchers). In our work, both the researchers and participants have helped to write summaries of the findings. These summaries are shared with the steering committee, who approve reports before they are released. We have also found it useful to prepare short, newsletter style summaries, which can be widely circulated both within and outside the settings, as well as longer reports which provide more detail. Finally, consumer/survivors and researchers can jointly make presentations to research participants and settings, as well as to broader audiences at conferences or workshops, to share what they have learned (Rapp *et al.*, 1993). We recently (March 1997) made a presentation of the initial findings of a current study at the American Orthopsychiatry Conference in Toronto (Nelson *et al.*, 1996). Consumer/survivors, students, and senior researchers all played a part in the presentation, and consumer/survivors responded effectively to challenging questions from mental health professionals and researchers in the audience.

Recommendations for Substantive Areas of Inquiry

In addition to some practical methodological steps that may be taken, the values we have set forth may also be enhanced by further attention to substantive areas regarding self-help/mutual aid organizations. While the particular substantive areas that self-help/mutual aid organizations want to focus on depends on the unique context and needs of each organization, we see several general substantive areas of inquiry that fit with the values

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

of these organizations. We believe it is important for researchers to concentrate on the goals and methods of self-help/mutual aid (e.g., empowerment, social support), rather than trying to force research on self-help/mutual aid into addressing questions that are more pertinent to treatment programs (e.g., a focus on psychiatric symptoms) (Trainor *et al.*, 1997).

Empowerment

We recommend further research to *examine the personal and collective empowerment of psychiatric consumer/survivors*. One aspect of personal empowerment is the extent to which consumer/survivors become less dependent on formal mental health services. While many consumer/survivors find it important and useful to use treatment services, consumer/survivors also recognize their need for independence. Several studies of self-help/mutual aid organizations for consumer/survivors have found reductions in rates of rehospitalization and use of other mental health services with active participation in self-help/mutual aid (Edmunson, Bedell, & Gordon, 1984; Kennedy, 1989; Trainor *et al.*, 1997; Trainor & Tremblay, 1992). Government stakeholders are also likely to be interested in this outcome, as they are increasingly concerned with cost containment and resource allocation.

Reducing the use of mental health services, however, is, by itself, a limited indicator of personal empowerment. Personal empowerment also refers to perceptions and experiences of control, active participation, and life enrichment (Kyrouz & Humphreys, 1996; Rappaport, 1987). Thus, both qualitative (Kennedy & Humphreys, 1994; Lord & Hutchison, 1993; Trainor *et al.*, 1997) and quantitative (Rapp *et al.*, 1993; Segal *et al.*, 1995; Trainor *et al.*, 1997) methods to assess the process and outcomes of personal empowerment in the context of self-help/mutual aid are needed.

Finally, although empowerment has been conceptualized as a multilevel, ecological construct (Rappaport, 1987), much of the research on empowerment has focused on the individual level of analysis. We believe it is important to move beyond personal or psychological empowerment to *engage in research and action that seeks to eradicate oppressive structures and processes and to encourage empowerment on a larger political and organizational scale*. Recently, Segal *et al.* (1995) have studied organizational and community dimensions of empowerment for psychiatric consumer/survivors in the context of self-help/mutual aid organizations. Further research which connects the "personal and the political" and which examines contextual factors which contribute to empowerment is needed. To this end, we can learn from the tradition of feminist research which shares many of the val-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

ues of participatory action research (Kirby & McKenna, 1989; Reinharz, 1992).

Supportive Relationships

To date, research related to the value of supportive relationships for psychiatric consumer/survivors in self-help/mutual aid organizations has focused on the social networks and social support processes among consumer/survivors. However, according to Kyrouz and Humphreys's (1996) review, there is as yet no evidence that participation in self-help/mutual aid organizations is accompanied by increases in one's social network, social support, or experience of a psychological sense of community. Since these are key aspects of the ethos of self-help/mutual aid, we recommend that there be a *focus on how self-help/mutual aid organizations contribute to consumer/survivors' social support and sense of community*. Trainor *et al.* (1997) found that consumer/survivor participation in a self-help/mutual aid organization was associated with participation in the community.

Prilleltensky and Nelson (1997) have argued that research and action are needed that is related to connections between different stakeholders, as well as connections within a stakeholder group. In the psychiatric consumer/survivor movement, we need to learn more from "bridgers," that is, people who are well positioned in both the consumer/survivor community and in other networks. These bridgers often assume leadership positions and serve as change agents. For example, in Church's work (1995), one consumer/survivor, who was also a politician in the provincial government, played an instrumental role in bringing consumer/survivors into a consultation process on government community mental health legislation. There are others, including professionals, who are involved in and can serve to bridge or make connections between the consumer/survivor and nonconsumer/survivor worlds, whose experiences would be valuable to learn more about.

Social Change

We need to *pay greater attention to the social change aspects of self-help/mutual aid organizations for psychiatric consumer/survivors*. As Humphreys and Rappaport (1994) noted in their review, most of the research on self-help/mutual aid has been concerned with the interpersonal support aspects of these groups and organizations. However, many self-help/mutual aid organizations for psychiatric consumer/survivors have an advocacy and social change focus. With the exception of the work of Church (1993, 1995,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

1996), there has not been much research focusing on the social change activities of these organizations. It would be interesting to know what influence self-help/mutual aid organizations for psychiatric consumer/survivors have had on mainstream mental health organizations, the policy and planning process, and other community settings. Since many governments have initiated "mental health reform," it would be important to note how the presence or absence of self-help/mutual aid organizations for psychiatric consumer/survivors has had an impact on such change processes. Also, we have much to learn from consumer/survivors who have started their own businesses and other community economic development initiatives (Church, 1997). Rapp *et al.* (1993) have discussed the importance of researching employment interventions for consumer/survivors, using a multilevel ecological, empowerment approach.

Learning as an Ongoing Process

Another recommendation that we have is to *learn more about the stories of consumer/survivor-controlled self-help/mutual aid organizations*. Rappaport (1993) has argued that self-help/mutual aid organizations for psychiatric consumer/survivors have their own "community narratives," and that these narratives play an important role in the lives of individual members. To date, there has been some research which looks at the stories of individual members of self-help/mutual aid organizations, but there has been little research regarding the organizational or community narratives of such settings. One exception is the study of the creation of a self-help/mutual aid organization for psychiatric consumer/survivors by Bargal (1992). The stories of how such alternative settings are created and develop over time would be very instructive, since such organizations usually operate with little external support and often face opposition from mainstream mental health settings. We also need to learn more about the features of successful partnerships between consumer/survivors and professionals (Lord, Ochocka, Czarny, & MacGillivary, 1998; MacGillivary & Nelson, in press).

Summary

We have made a number of recommendations of how the values of empowerment, supportive relationships, social change, and learning as an ongoing process can be promoted in both methodology and substantive areas of inquiry in participatory action research with self-help/mutual aid or-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table II. Recommendations for Methodology and Substantive Areas of Inquiry in Participatory Action Research with Self-Help/Mutual Aid Organizations for Psychiatric Consumer/Survivors

Assumptions/values	Methodology	Substantive areas of inquiry
Empowerment	Use research steering committees Greater use of qualitative methods	Examine personal and collective empowerment Engage in research and action that seeks to eradicate oppressive structures and processes and to encourage empowerment on a larger political and organizational scale
Supportive relationships	Develop authentic and supportive relationships Write about personal experiences in research articles	Focus on how self-help/mutual aid organizations contribute to consumer/survivors' social support and sense of community Learn more from "bridgers"
Social change	Hire consumer/survivor researchers Locate a group or groups to use the research findings for education and/or advocacy	Pay greater attention to the social change aspects of self-help/mutual aid organizations
Learning as an ongoing process	Use emergent (or flexible) research designs Provide an educational component	Learn more about the stories of self-help/mutual aid organizations

ganizations for psychiatric consumer/survivors. In Table II, we provide a summary of these recommendations.

CONCLUSION

We have tried to reflect our commitment to "theory in the making" (hooks, 1984). Our theories are evolving at the same time that we are learning from our continued collaborations with consumer/survivor organizations. We want to emphasize how important it has been for us to go gently into this whole area and how our experiences, while not without some conflicts, have been mostly positive. We know that some colleagues who have used participatory action research approaches with consumer/survivors have encountered difficulties and challenges that are both personally and professionally taxing. Effective dialogue has become a central principle in our work with consumer/survivors. We have learned to listen and to respect strengths and differences, to strive for better relationships and to celebrate ourselves and others, to create contexts that enable consumer/survivors to feel safe in collaborating for change, and to raise consciousness and promote education. Yet we recognize that these steps in living our values are "small beginnings" in the journey to build strong collaborative partnerships

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

between participatory action research and self-help mutual aid organizations for consumer/survivors. Although we may believe that we are being consistent with our values, those with whom we work may have different views. Thus, it is important to engage in a process of open dialogue with participants about our role as researchers and whether we are being true to our values. What we have learned resonates with the following quote from Lily Walker: "If you are here to help me then you are wasting your time, but if you are here because your liberation is bound with mine, then let us begin" (Lily Walker, date and source unknown).

REFERENCES

Argyris, C., & Schön, D. (1978). *Organizational learning.* Reading, MA. Addison-Wesley.

Bargal, D. (1992). The early stage in the creation of two self-help organizations: An exploratory study. *Administration in Social Work, 16*(3/4), 81-98.

Barnsley, J., & Ellis, D. (1992). *Research for change: Participatory action research for community groups.* Vancouver, BC: Women's Research Centre.

Borkman, T. J. (1990). Experiential, professional, and lay frames of reference. In T. J. Powell (Ed.), *Working with self-help* (pp. 3-30). Silver Spring, MD: National Association of Social Workers.

Borkman, T. J., & Schubert, M. (1994). Participatory action research as a strategy for studying self-help groups internationally. *Prevention in Human Services, 11,* 45-68.

Brown, L. D., & Tandon, R. (1983). Ideology and political economy in inquiry: Action research and participatory research. *Journal of Applied Behavioral Science, 19,* 277-294.

Burstow, B., & Weitz, D. (Eds.). (1988). *Shrink resistant: The struggle against psychiatry in Canada.* Vancouver, BC: New Star Books.

Capponi, P. (1992). *Upstairs in the crazy house: The life of a psychiatric survivor.* Toronto: Viking.

Carling, P. J. (1995). *Return to community: Building support systems for people with psychiatric disabilities.* New York: Guilford.

Chamberlin, J. (1978). *On our own: Patient-controlled alternatives to the mental health system.* New York: McGraw-Hill.

Chamberlin, J. (1990). The ex-psychiatric patients' movement: Where we've been and where we're going. *Journal of Mind and Behavior, 11,* 323-336.

Chamberlin, J., & Rogers, J. A. (1990). Planning a community-based mental health system: Perspective of service recipients. *American Psychologist, 45,* 1241-1244.

Chamberlin, J., Rogers, E. S., & Ellison, M. L. (1996). Self-help programs: A description of their characteristics and their members. *Psychiatric Rehabilitation Journal, 19,* 33-42.

Chesler, M. A. (1991). Participatory action research with self-help groups: An alternative paradigm for inquiry and action. *American Journal of Community Psychology, 19,* 757-768.

Church, K. (1993). *Breaking down/breaking through: Multi-voiced narratives on psychiatric survivor participation in Ontario's community mental health system.* Doctoral dissertation, University of Toronto.

Church, K. (1994). *Working together across differences: An invitational symposium and how it grew.* Toronto: Psychiatric Survivor Leadership Facilitation Program and Community Resources Consultants of Toronto.

Church, K. (1995). *Forbidden narratives: Critical autobiography as social science.* Amsterdam: Gordon and Breach.

Church, K.(1996). Beyond "bad manners": The power relations of "consumer participation" in Ontario's community mental health system. *Canadian Journal of Community Mental Health, 15*(2), 27-44.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Church, K. (1997). *Because of where we've been: The business behind the business of psychiatric survivor economic development.* Available from 761 Community Development Corporation, 761 Queen Street West, 3rd Floor, Toronto, Ontario, M6J 1G1.

Church, K., & Creal, L. (1995a). *Voices of experience: Five tales of community economic development in Toronto.* Available from Fred Victor Centre, 145 Queen Street East, Toronto, Ontario.

Church, K., & Creal, L. (1995b). *Working the margins: Qualitative dimensions of community economic development in Toronto.* Available from 761 Community Development Corporation, 761 Queen Street West, 3rd Floor, Toronto, Ontario, M6J 1G1.

Church, K., & Reville, D. (1989). User involvement in the mental health field in Canada. *Canada's Mental Health, 37*(2), 22-25.

Constantino, V., & Nelson, G. (1995). Changing relationships between self-help groups and mental health professionals: Shifting ideology and power. *Canadian Journal of Community Mental Health, 14*(2), 55-70.

Corrigan, P. W., & Garman, A. N. (1997). Considerations for research on consumer empowerment and psychosocial interventions. *Psychiatric Services, 48,* 347-352.

Curtis, L. C., & Hodge, M. (1994). Old standards, new dilemmas: Ethics and boundaries in community support services. *Psychosocial Rehabilitation Journal, 18,* 13-33.

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1997, May). *Peer support among individuals with severe mental illness: History, roadblocks, and a review of the evidence.* Paper presented at the Self-Help Research Pre-Conference, Society for Community Research and Action Biennial Conference, Columbia, South Carolina.

Edmunson, E. D., Bedell, J. R., & Gordon, R. E. (1984). The Community Network Development Project: Bridging the gap between professional aftercare and self-help. In A. Gartner & F. Riessman (Eds.), *The self-help revolution* (pp. 195-203). New York: Human Sciences.

Emerick, R. E. (1990). Self-help groups for former patients: Relations with mental health professionals. *Hospital and Community Psychiatry, 41,* 401-407.

Everett, B. (1994). Something is happening: The contemporary consumer and psychiatric survivor movement in historical context. *Journal of Mind and Behavior, 15,* 55-69.

Freire, P. (1970). *Pedagogy of the oppressed.* New York: Seabury.

Gaventa, J. (1993). The powerful, the powerless, and the experts: Knowledge struggles in an information age. In P. Park, M. Brydon-Miller, B. Hall, & T. Jackson (Eds.), *Voices of change: Participatory research in the United States and Canada* (pp. 21-40). Westport, CT: Bergen and Garvey.

Hall, B. (1993). Introduction. In P. Park, M. Brydon-Miller, B. Hall, & T. Jackson (Eds.), *Voices of change: Participatory research in the United States and Canada* (pp. xiv-xii). Westport, CT: Bergen and Garvey.

Hooper, K. (1987). *The anti-electroconvulsive therapy movement in Ontario: A description and analysis.* Unpublished Master's thesis, Wilfrid Laurier University, Waterloo, ON.

hooks, B. (1984). *From margin to center.* Boston: South End.

Humphreys, K. (Ed.).(1996). Self-help/mutual aid initiatives by people with psychiatric disabilities [Special section]. *Community Psychologist, 29,* 9-25.

Humphreys, K., & Rappaport, J. (1994). Researching self-help/mutual aid groups and organizations: Many roads, one journey. *Applied and Preventive Psychology, 3,* 217-231.

Kennedy, M. (1989). *Psychiatric rehospitalization of GROWers.* Paper presented at the Biennial Conference of the Society for Community Research and Action, East Lansing, MI.

Kennedy, M., & Humphreys, K. (1994). Understanding world view transformation in members of mutual help groups. *Prevention in Human Services, 11,* 181-198.

Kennedy, M., Humphreys, K., & Borkman, T. (1994). The naturalistic paradigm as an approach to research with mutual-help groups. In T. Powell (Ed.), *Understanding the self-help organization* (pp. 172-189). Thousand Oaks, CA: Sage.

Kessler, R. C., Mickelson, K. D., & Zhao, S. (1997). Patterns and correlates of self-help group membership in the United States. *Social Policy, 27*(3), 27-46.

Kirby, S., & McKenna, K. (1989). *Experience, research, social change: Methods from the margins.* Toronto: Garamond.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Kofman, F., & Senge, P. M. (1993). Communities of commitment: The heart of learning organizations. *Organizational Dynamics, 22,* 5-23.

Kroeker, C. J. (1996). The cooperative movement in Nicaragua: Empowerment and accompaniment of severely disadvantaged peasants. *Journal of Social Issues, 52,* 123-138.

Kyrouz, E., & Humphreys, K. (1996). Do psychiatrically disabled people benefit from participation in self-help/mutual aid organizations? A research review. *Community Psychologist, 29*(3), 21-25.

Lavoie, F. (1984). Action research: A new model of interaction between the professional and self-help groups. In A. Gartner & F. Riessman (Eds.), *The self-help revolution* (pp. 173-182). New York: Human Sciences.

Leff, H. S., Campbell, J., Gagne, C., & Woocher, L. S. (1997). Evaluating peer providers. In C. T. Mowbray, D. P. Moxley, C. A. Jasper, & L. L. Howell (Eds.), *Consumers as providers in psychiatric rehabilitation* (pp. 488-501). Columbia, MD: IAPSRS Press.

Levine, M., & Perkins, D. V. (1997). *Principles of community psychology: Perspectives and applications* (2nd ed.). New York: Oxford University Press.

Lewin, K. (1946). Action research and minority problems. *Journal of Social Issues, 2,* 34-46.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Beverly Hills, CA: Sage.

Lincoln, Y. S., & Guba, E. G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. In *New directions for program evaluation* (Vol. 30, pp. 73-84). San Francisco: Jossey-Bass.

Lord, J., & Hutchison, P. (1993). The process of empowerment: Implications for theory and practice. *Canadian Journal of Community Mental Health, 12*(1), 5-22.

Lord, J., & Ochocka, J. (1995). Outcomes of an individualized family support program. *Journal of Leisurability, 22*(4), 22-32.

Lord, J., Ochocka, J., Czarny, W., & MacGillivary, H. (1998). Analysis of change within a mental health organization: A participatory process. *Psychiatric Rehabilitation Journal, 21,* 327-339.

Lord, J., Schnarr, A., & Hutchison, P. (1987). The voice of the people: Qualitative research and the needs of consumers. *Canadian Journal of Community Mental Health, 6*(2), 25-36.

MacGillivary, H., & Nelson, G. (in press). Partnership in mental health: What it is and how to do it. *Canadian Journal of Rehabilitation.*

McKnight, J. (1995). *The careless society: Community and its counterfeits.* New York: Basic Books.

Morrell-Bellai, T. L., & Boydell, K. M. (1994). The experience of mental health consumers as researchers. *Canadian Journal of Community Mental Health, 13*(1), 97-110.

Nelson, G. (1994). The development of a mental health coalition: A case study. *American Journal of Community Psychology, 22,* 229-255.

Nelson, G., Lord, J., & Ochocka, J. (1996). *Progress report—Shifting the paradigm in community mental health: A community study of implementation and change: Phase I—Historical and policy context.* Unpublished document, Centre for Research and Education in Human Services, Kitchener, ON.

Nelson, G., Walsh-Bowers, R., & Hall, G. B. (1998). Housing for psychiatric survivors: Values, policy, and research. *Administration and Policy in Mental Health, 25,* 455-462.

Ochocka, J., Roth, D., Lord, J., & MacNaughton, E. (1993). *Support Clusters Project: Evaluation report of a research demonstration project.* Kitchener, ON: Centre for Research and Education in Human Services.

Papineau, D., & Kiely, M. C. (1996). Participatory evaluation in a community organization: Fostering stakeholder empowerment and utilization. *Evaluation and Program Planning, 19,* 79-93.

Park, P. (1993). What is participatory research? A theoretical and methodological perspective. In P. Park, M. Brydon-Miller, B. Hall, & T. Jackson (Eds.), *Voices of change: Participatory research in the United States and Canada* (pp. 1-19). Westport, CT: Bergen and Garvey.

Park, P., Brydon-Miller, M., Hall, B., & Jackson, T. (Eds.). (1993). *Voices of change: Participatory research in the United States and Canada.* Westport, CT: Bergen and Garvey.

Patterson, C. (1992). *Thesis-making: Reflections on my experience.* Unpublished master's thesis, Wilfrid Laurier University, Waterloo, ON.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Pomeroy, E., Church, K., & Trainor, J. (1987). A report on the CMHA search conference on the chronically mentally disabled. *Canadian Journal of Community Mental Health, 6*(2), 149-151.

Powell, T. J., & Cameron, M. J. (1991). Self-help research and the public mental health system. *American Journal of Community Psychology, 19,* 797-805.

Prilleltensky, I., & Nelson, G. (1997). Community psychology: Reclaiming social justice. In D. Fox & I. Prilleltensky (Eds.), *Critical psychology: An introduction* (pp. 166-184). London: Sage.

Raiff, N. R. (1984). Some health related outcomes of self-help participation: Recovery, Inc. as a case example of a self-help organization in mental health. In A. Gartner & F. Riessman (Eds.), *The self-help revolution* (pp. 183-193). New York: Human Sciences.

Rapp, C. A., Shera, W., & Kisthardt, W. (1993). Research strategies for consumer empowerment of people with severe mental illness. *Social Work, 38,* 727-735.

Rappaport, J. (1987). Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. *American Journal of Community Psychology, 15,* 121-144.

Rappaport, J. (1993). Narrative studies, personal stories, and identity transformation in the mutual help context. *Journal of Applied Behavioral Science, 29,* 239-256.

Rappaport, J., Seidman, E., Toro, P. A., McFadden, L. S., Reischl, T. M., Roberts, L. J., Salem, D. A., Stein, C. H., & Zimmerman, M. A. (1985). Finishing the unfinished business: Collaborative research with a mutual help organization. *Social Policy, 16,* 12-24.

Reason, P. (1994). Three approaches to participative inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 324-339). Thousand Oaks, CA: Sage.

Reinharz, S. (1992). *Feminist methods in social research.* Oxford, U.K.: Oxford University Press.

Ristock, J. L., & Pennell, J. (1996). *Community research as empowerment: Feminist links, postmodern interruptions.* Toronto: Oxford University Press.

Roberts, L. J., Luke, D. A., Rappaport, J., Seidman, E., Toro, P. A., & Reischl, T. M. (1991). Charting unchartered terrain: A behavioral observation system for mutual help groups. *American Journal of Community Psychology, 19,* 715-737.

Rogers, E. S., Chamberlin, J., Ellison, M. L., & Crean, T. (1997). A consumer-constructed scale to measure empowerment among users of mental health services. *Psychiatric Services, 48,* 1042-1047.

Rogers, E. S., & Palmer-Erbs, V. (1994). Participatory action research: Implications for research and evaluation in psychiatric rehabilitation. *Psychosocial Rehabilitation Journal, 18*(2), 4-11.

Saleeby, D. (Ed.).(1992). *The strengths perspective in social work practice.* New York: Longman.

Sarason, S. B. (1988). *The psychological sense of community: Prospects for a community psychology* (rev. ed.). Cambridge, MA: Brookline.

Segal, S. P., Silverman, C., & Temkin, T. (1995). Measuring empowerment in client-run self-help agencies. *Community Mental Health Journal, 31,* 215-227.

Senge, P. (1990a). The leader's new work: Building learning organizations. *Sloan Management Review, 32,* 7-23.

Senge, P. (1990b). *The fifth discipline: The art and practice of the learning organization.* New York: Doubleday Currency.

Smith, J. A. (1994). Towards reflexive practice: Engaging participants as coresearchers or coanalysts in psychological inquiry. *Journal of Community and Applied Social Psychology, 4,* 253-260.

Srebnick, D., Robinson, M., & Tanzman, B. (1990, August). *Participation of mental health consumers in research: Empowerment in practice.* Poster presentation at the annual meeting of the American Psychological Association, Boston, MA.

Stringer, E. T. (1996). *Action research: A handbook for practitioners.* Thousand Oaks, CA: Sage.

Torrey, E. F. (1997). Psychiatric survivors and nonsurvivors. *Psychiatric Services, 48,* 143.

Trainor, J., Pomeroy, E., & Pape, B. (1993). *A new framework for support for people with serious mental illness.* Toronto: Canadian Mental Health Association/National Office.

Trainor, J., Shepherd, M., Boydell, K. M., Leff, A., & Crawford, E. (1997). Beyond the service paradigm: The impact and implications of consumer/survivor initiatives. *Psychiatric Rehabilitation Journal, 21,* 132-140.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Trainor, J., & Tremblay, J. (1992). Consumer/survivor businesses in Ontario: Challenging the rehabilitation model. *Canadian Journal of Community Mental Health, 11*(2), 65-71.

Weitz, D. (1984). "On Our Own": A self-help model. In D. P. Lumsden (Ed.), *Community mental health action: Primary prevention programming in Canada* (pp. 312-320). Ottawa: Canadian Public Health Association.

Whitmore, E. (1991). Evaluation and empowerment: It's the process that counts. *Networking Bulletin: Empowerment and Family Support, 2*(2), 1-7.

Woodside, H., & Cikalo, P. (1995). Collaborative research: Perspectives on consumer-professional partnerships. *Canada's Mental Health, 43*(1), 2-6.

Yeich, S. (1996). Grassroots organizing with homeless people: A participatory research approach. *Journal of Social Issues, 52,* 111-121.

Yeich, S., & Levine, R. (1992). Participatory research's contribution to a conceptualization of empowerment. *Journal of Applied Social Psychology, 22,* 1894-1908.

Zimmerman, M. A., Reischl, T. M., Seidman, E., Rappaport, J., Toro, P. A., & Salem, D. A. (1991). Expansion strategies of a mutual help organization. *American Journal of Community Psychology, 19,* 251, 278.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.