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A COMPREHENSIVE EVALUATION FRAMEWORK FOR MENTAL HEALTH CONSUMER/SURVIVOR ORGANIZATIONS: VALUES, CONCEPTUALIZATION, DESIGN, AND ACTION

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Abstract: This article provides a framework for the evaluation of mental health consumer/ survivor organizations that consists of four main components: (a) participatory processes, (b) conceptualization of the activities and outcomes at the individual and systems levels of these organizations, (c) the combination of quantitative and qualitative methods for examining activities and outcomes, and (d) dissemination and action. We assert that these components form a comprehensive and holistic framework for evaluating mental health consumer/survivor organizations; we illustrate how these components can be put into action through a case study of four mental health consumer/survivor organizations in Ontario; and we reflect on the lessons that we have learned in conducting this evaluation.

Résumé: Dans cet article, nous proposons un cadre pour l'évaluation des organisations de consommateurs de services de santé mentale. Ce cadre comprend quatre grandes composantes: (a) les processus de participation, (b) la conceptualisation des activités et des effets tant au niveau personnel que des systèmes de ces organi-

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sations, (c) la combinaison de méthodes quantitatives et qualitatives pour examiner les activités et les effets, et (d) la dissémination et l'action. Nous soutenons que ces composantes constituent un cadre détaillé et global pour l'évaluation des organisations de consommateurs des services de santé mentale; nous illustrons comment ces composantes peuvent être mises en œuvre par l'entremise d'une étude de cas de quatre organisations de consommateurs en Ontario. Finalement, nous nous penchons sur les leçons apprises dans la réalisation de cette évaluation.

In this article, we describe a comprehensive evaluation framework that we argue is a good “fit” for mental health consumer/survivor organizations, and we provide a case example of this framework in action through an evaluation of four Consumer/Survivor Initiatives (CSIs) in southern Ontario. Note that the focus of this article is on the evaluation framework rather than on the findings of the evaluation or the process of conducting the evaluation, which we will report in other articles. We begin by describing and providing some background on mental health consumer/survivor organizations.

MENTAL HEALTH CONSUMER/SURVIVOR ORGANIZATIONS

The emergence of consumer-run organizations is best viewed within the context of deinstitutionalization. In many jurisdictions, including Ontario, this process began in the 1960s and was not well conceived or carried out. The complexity of supporting consumers in the community and the range of roles played by older institutional settings were both underestimated (Simmons, 1990). As a result, many people, particularly those with more serious mental illness, were not provided with sufficient support in the community. The main indicators of what became widely recognized as a crisis situation were homelessness, poverty, unemployment, and social alienation.

Following the end of the initial period of bed closures (about 1975 in Ontario), attempts were made to deal with the desperate conditions faced by many consumers. These attempts can be broadly characterized under three headings: (a) improvements in treatment services (e.g., Assertive Community Treatment Teams); (b) new services centred on determinants of health such as housing, work, and social support; and (c) consumer-run organizations.

Consumer-run organizations have emerged from different historical roots and in a variety of forms using different models of action. As a result, the history of consumers taking action on their own behalf is multi-faceted. The self-help movement was one major antecedent of consumer-run organizations. It gave birth to groups for many kinds of disability, with examples in mental health such as Recovery Incorporated and GROW dating from the 1930s and 1950s respectively (Galanter, 1988; Lee, 1995; Omark, 1979; Powell, 1975). According to Zimmerman et al. (1991), the main goal of these self-help organizations was to integrate members back into the community without interfering with the mental health system or threatening the role of professionals. The focus was on individual action and responsibility.

A second root, the ex-patients' movement, described by Chamberlin (1990), can be traced back to the late 1960s and early 1970s. Many of the groups in this movement were advocacy oriented and sharply critical of mental health and psychiatric practice (Chamberlin; McLean, 1995; Shelton & Rissmeyer, 1989). They focused attention on the system, including its institutional and ideological components, rather than the individual. In this sense they differed sharply from the self-help movement as typified by Recovery Incorporated.

In both the U.S. and Canada a new generation of consumer-run organizations began to emerge in the 1980s. Given the crisis of deinstitutionalization, state and provincial mental health authorities became more interested in these groups and began to provide funding and other kinds of support. To take two examples, in 1989 the National Association of State Mental Health Program Directors approved a position paper that recognized the contribution that consumer/survivors can make to mental health care, and in 1990 the province of Ontario began to direct funding to consumer/survivor-controlled initiatives and to recognize them as a legitimate part of the mental health system (Campbell & Leaver, 2003; Trainor, Shepherd, Boydell, Leff, & Crawford, 1997). In the U.S., consumer/survivors now operate a wide range of organizations that are often supported by public funds. These include mutual support groups, peer-run multi-service agencies, peer-run drop-in programs, and peer-run education and advocacy programs (Campbell & Leaver). In Canada, the focus of consumer/survivor organizations has been on activities using the principles of self-help and mutual aid rather than the delivery of mental health services (Trainor et al.). Despite this, the spirit of the programs in both countries is similar, with the central concepts being empowerment and recovery.

Consumer/survivors use CSIs in different ways. For some, involvement serves as a support that is in addition to conventional treatment, and for others as an alternative to it. The latter group do not want any participation in conventional services (Segal, Silverman, & Temkin, 1993). Other consumer/survivors are concerned that the new focus on evidence-based practice is leading to a narrow range of program models and as a result is limiting choice and stifling innovation (Frese, Stanley, Kress, & Vogel-Scibilia, 2001). They see CSIs as a source of choice and of new ideas that come from people who experience mental illness.

However the use of CSIs is framed, they tend to share common goals. These include the provision of safe supportive community environments, promoting an atmosphere of acceptance, an emphasis on dignity and self-worth, and learning from and helping one another (Tan, Mowbray, & Foster, 1990). These goals are set in a context of recovery and empowerment that encourages people to confront and overcome the negative input they may have received from families, treatment staff, and the larger society. Key to this process is the issue of power, and CSIs attempt to use practices that rebalance power (Chamberlin, 1990; Segal et al., 1993). By acting on their own behalf, helping others, and sharing their personal narratives, consumer/survivors develop resiliency and rebuild a positive identity (McLean, 1995; Mead, Hilton, & Curtis, 2001).

In Ontario, where the present study was conducted, the development of CSIs began in earnest in 1990 with the launching of the Consumer/Survivor Development Initiative (now the Ontario Peer Development Initiative). This directed funding to consumer-controlled organizations and supported them in developing a range of activities. The key restriction of the funding was the prohibition of CSIs offering traditional mental health services that involved the roles of client and worker. Instead, organizations pursued their goals using the principles of self-help and mutual aid (Trainor et al., 1997). There are now more than 60 CSIs across the province that work in one or more of the areas of self-help, knowledge development and skills training, public and professional education, advocacy, business development and operation, and cultural activities. They are funded by the provincial Ministry of Health and Long-Term Care as part of its community mental health budget.

THE FRAMEWORK

What kind of approach is best suited to the evaluation of these types of organizations? In this section, we describe an evaluation framework with four primary components: (a) participatory processes, (b) conceptualization of the activities and outcomes at the individual and systems levels of these organizations, (c) the combination of quantitative and qualitative methods for examining activities and outcomes, and (d) dissemination and action. While this framework is not new to the evaluation field, we argue that it is particularly well-suited to the ethos of mental health consumer/survivor organizations. In this section, we outline the main components of the framework, and we illustrate how this framework can be put into practice by describing an evaluation of four CSIs in southern Ontario. This evaluation was one of several evaluations of different types of community mental health services that was funded by the provincial Ministry of Health and Long-Term Care under the auspices of the Community Mental Health Evaluation Initiative (CMHEI) (Dewa et al., 2002). All of the evaluations involved a longitudinal follow-up of program participants.

Valuing Participatory Processes

In this longitudinal evaluation we wanted to have a successful process, as well as a rigorous methodology. In this section we emphasize the importance of participatory processes in evaluation research; we introduce the notion of value commitment in the evaluation process, including a commitment to power-sharing, relationship-building, and shared ownership and control of the evaluation; and we also illustrate the mechanisms that we used to implement these values.

Participatory approaches that emphasize multiple perspectives and a collaborative, dialogic process of constructing knowledge are increasingly being developed and applied to evaluation research (e.g., Bradley, Mayfield, Mehta, & Rukonge, 2002; Cousins & Earl, 1986). There is growing awareness in the research community of the need to employ methodologies that are appropriate for the unique circumstances of the communities being studied (Fisher & Ball, 2003). There is also an increasing recognition that evaluation research needs to be credible and relevant to stakeholders to be utilized (Patton, 1997).

Participatory approaches have been described as representing the stance that knowledge is produced in collaboration (Fine et al., 2003), for the purpose of enhancing the ownership and use of the evaluation findings (Brandon, 1998; Cousins & Earl, 1986) and for promoting social change and empowerment (Greene, 2000). Despite certain differences, “collaborative and participatory” (Cousins & Earl), “participatory action” (Fals-Borda & Rahman, 1991), and “empowerment” (Fetterman, 2001) approaches to evaluation resemble each other in many ways. For example, empowerment evaluation has emphasized giving more decision-making control to stakeholders, while participatory action evaluation is more about liberating oppressed people and social action (Fals-Borda & Rahman). All three approaches share two common commitments: the extensive participation of stakeholders and a focus on utilization of evaluation findings (Fetterman).

For the purpose of this evaluation, we used a participatory action research (PAR) approach to evaluation that is rooted in the tradition of democratic pluralism, social change, and empowerment. PAR can be defined as a “research approach that involves active participation of stakeholders, those whose lives are affected by the issue being studied, in all phases of research for the purpose of producing useful results to make positive changes” (Nelson, Ochocka, Griffin, & Lord, 1998, p. 12). This approach is particularly well suited to research *with* CSIs. Members of CSIs don’t want to be “research subjects” but rather “active partners” in the research process (Rappaport et al., 1985). CSIs are also member-driven and are interested in something that they believe is meaningful and will be useful for the organizations and its members. We argue that because a PAR approach to evaluation and self-help/mutual aid groups share many values in common (Nelson et al.), PAR was particularly appropriate and effective for the evaluation of CSIs. This value-driven approach influenced all of our methodological and substantive decisions and was embedded within the research processes.

We believe that PAR evaluation is most importantly a value commitment to democratic pluralism that “is broadening the policy conversation to include all legitimate perspectives and voices and to full and fair stakeholder participation in policy and program decision-making” (Ryan, Green, Lincoln, Mathison, & Mertens, 1998, p. 109) and to diversity and inclusion. The social action orientation of PAR, described later in this article, also helps to broaden and deepen the dialogue about important social issues and ways of addressing them.

From our previous work, we recognized four values guiding PAR that are congruent with the values of consumer/survivor organizations: (a) empowerment, (b) supportive relationships, (c) social change, and (d) learning as an ongoing process (Nelson et al., 1998; Ochocka, Janzen, & Nelson, 2002). We, the researchers, have creatively developed principles and strategies for implementing these four values throughout the evaluation process.

In terms of *empowerment* we have the principle of evaluating *with*, not *on* or *for*, the consumer community (Stringer, 1996). From the beginning of the study we worked closely with the Ontario Peer Development Initiative (OPDI), an umbrella organization for roughly 60 CSIs in Ontario. When the call for proposals was announced, the researchers met with the coordinator of the OPDI to consider applying for a grant to evaluate the CSIs. We began by holding a series of meetings with representatives of several CSIs and the OPDI coordinator to develop the proposal collaboratively. Once we obtained funding for the research, the researchers and the OPDI coordinator together selected four CSIs for participation in the research.

Another strategy used to implement the value of empowerment was the use of a steering committee, composed of the executive directors of the four CSIs, the investigators and senior researchers who managed the project, an OPDI representative, and one CSI volunteer who chaired it since its inception. This steering committee was a forum where all decisions were made about the research activities undertaken, where knowledge and power were shared in all stages of the evaluation process, and where we achieved “a faithful representation” (Ryan et al., 1998, p. 117). As a committee we continually addressed power dynamics through an ongoing dialogue, following working principles and sharing research responsibilities. We shared not only work but also the rewards of the research, including co-presentations at conferences and co-authorship of some research publications (Reeve, Cornell, D’Costa, Janzen, & Ochocka, 2002).

The value of *supportive relationships* was implemented at the research team level (which consisted of consumer/survivor researchers and professional researchers), and also at the steering committee level. First, we were all very committed to valuing and using experiential knowledge. Each member of both teams was constantly acknowledged for bringing her/his own expertise related to research, CSIs, mental health or other issues. We listened to and learned from one other, and we also respected each other’s diversity, including

the culture and local practices of the four CSIs. Each monthly meeting of the research team involved training, supervision, debriefing, and support, in which professional and consumer/survivor researchers planned and reflected on research activities. Moreover, the research team did troubleshooting to ensure that the data were collected in a timely and appropriate manner. The steering committee and research team meetings were hosted in different sites at various locations and lasted from two to four hours. Skilled facilitation needs to be stressed as an important way to meaningfully and democratically involve all of the stakeholders, not just the most powerful or articulate.

In terms of *social* change, we hired consumer/survivor researchers to recruit participants and conduct the interviews. Over the course of the project we trained 15 consumer/survivor researchers. We also shared project resources with CSIs by covering the costs of travel and accommodation when meeting together or/and presenting at conferences. Also, all research participants were provided with an honorarium for each interview that they completed. In this way, consumer/survivors tangibly benefited from the research process.

We focused on giving back to the community. When we developed research tools, we tried to make them useful for CSI staff to enable them to continually collect information for documenting and reporting. We shared research findings in creative ways (community forums, presentations to the CSI boards and annual meetings, fact sheets, summary bulletins, etc.) to ensure that all participants owned and were able to use the evaluation results for advocacy. We disseminated information about CSIs to various audiences (policy, academic, local community), and we followed the principle of strong local participation and democratic decision-making, strategizing all activities with the big picture in mind, “think globally and always act locally” (Ryan et al., 1998, p. 112).

Our efforts to focus on concrete results and future change was also related to “*learning as we go*,” a value that emphasizes the educational component of PAR (Nelson et al., 1998; Park, 1993). We created educational opportunities for all involved by providing formal and informal training and support. But, most importantly, we created a learning culture. We are all learners, and this evaluation was an opportunity for all of us to gain an understanding of CSIs’ activities and impacts and creatively share our knowledge with various groups and stakeholders.

It was also important that the project was managed by the Centre for Research and Education in Human Services, a leader in PAR in Canada. The centre has a provincial and national reputation of working collaboratively with stakeholders when conducting research, and has a proven history of working with consumer/survivors and other mental health stakeholders on a number of research studies linked to policy and innovative practices. Having a community-based research centre to coordinate and link all partners created a safe community place for the study and all its players (Nelson, Lord, & Ochocka, 2001).

Our experience is that these four PAR values were essential for building trust, producing successful evaluation products, and enhancing communication and collaboration between the researchers and consumer/survivors (Nelson et al., 2001; Ochocka et al., 2002). However, this extensive participation and focus on action was not without dilemmas and challenges. For example, some of the consumer/survivor researchers experienced mental health and health challenges during the research and required extensive support from the senior researchers, including visiting these individuals while they were in hospital and staying in touch with them on a frequent basis to provide support. This also required the senior researchers to be flexible regarding the work schedules of some consumer/survivor researchers and to have other researchers do interviews or research tasks when needed.

Most of the consumer/survivor researchers were new to research, and some had not worked in paid employment for years. The senior researchers found that extensive training and supervision was needed throughout the study. A related challenge was that this was not a typical 9-to-5 job. Rather, consumer/survivor researchers had to work quite independently, organizing their work tasks and time schedule on their own. Regular meetings and frequent telephone contact with the consumer/survivor researchers who lived in three different regions was necessary to help them stay focused on the research and complete work tasks.

Another challenge was regular attendance at steering committee meetings for some members at some times. Staff members at the CSIs are often quite overextended because of the high volume of work and limited staff resources. The evaluation was one added responsibility. We rotated the location of meetings at the different sites and held conference calls on occasion to maximize participation of

CSI staff in the evaluation during the six-year period of the study. There were also staff changes at the CSIs and OPDI, with only one of the original executive directors of the CSI remaining in that position on the steering committee for the length of the study. Also, one of the CSIs went through a period of organizational turmoil during the study and was not attracting enough new members to participate in the study. The senior researchers decided to involve another CSI from the same region in the evaluation so that there would be an adequate sample of new CSI members for the study. The CSI that underwent organizational problems was also unable to complete some of the systems tracking data (to be described in a subsequent section), which was an important part of the evaluation.

We agree with Fine and her colleagues who state that “a crucial feature of participatory work is the building of a community of researchers — this means shared skills, respect, trust, and common language” (Fine et al., 2003, p. 189). While this type of evaluation has many challenges, we also believe that commitment to the identified values and to their implementation makes PAR evaluation successful.

Conceptualizing CSI Activities and Outcomes

In this section, we turn to our conceptualization of the research. In particular, we emphasize the use of program logic models in evaluation research and note their utility for framing research questions and methods. We also introduce the notion of an ecological framework that looks at systems as well as individuals, in terms of activities and outcomes, over time. We describe how we developed program logic models for each of the four CSIs and present an overall logic model that incorporates both individual and system activities and outcomes.

Near the beginning of the study, we as researchers wanted to gain an in-depth understanding of the activities and desired outcomes for each participating CSI. This was accomplished in stages and in a participatory manner. First, we collected and reviewed program documents from each site. Next, we held group and individual discussions with members and staff within each site. We asked them to list all their different activities and to explain what they hoped to achieve through these activities (i.e., short-term and long-term outcomes). Through the discussions and the document review it became clear that CSIs participated in two main kinds of activities: indi-

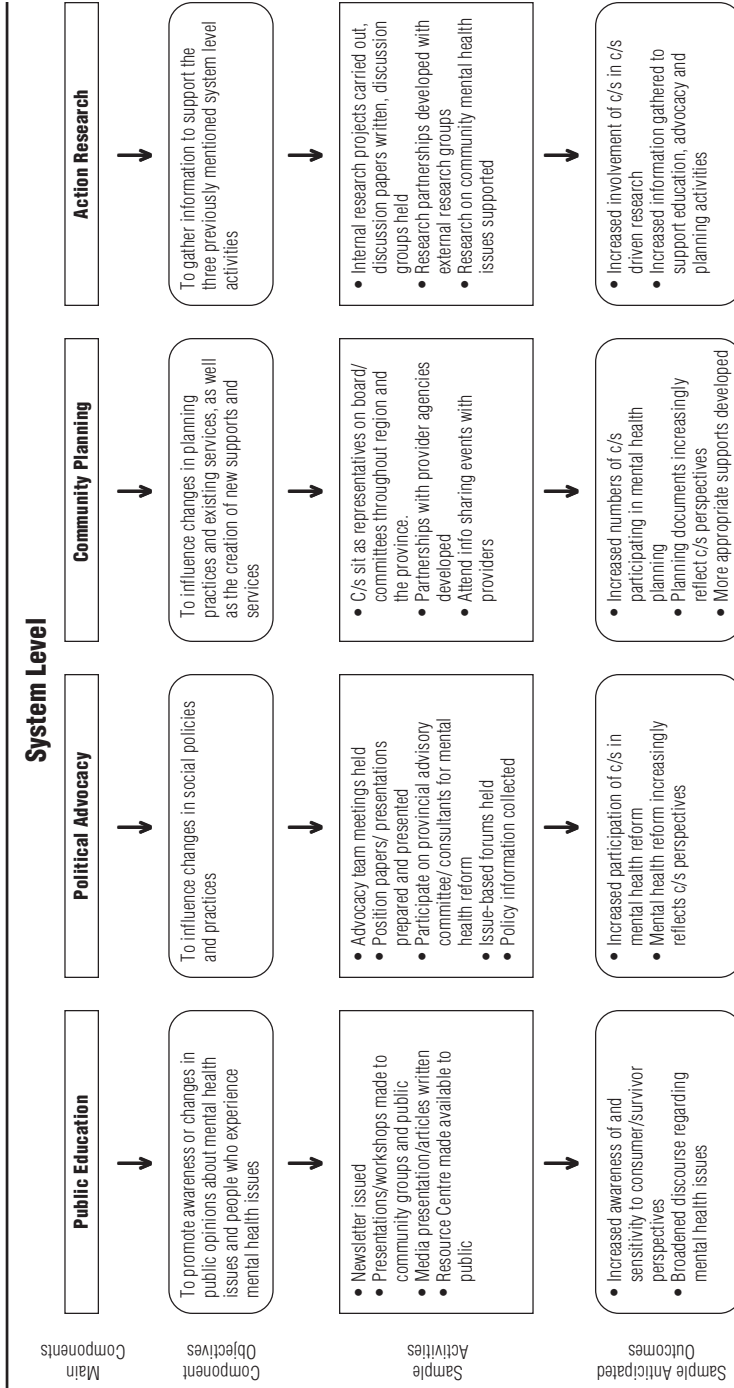
vidual-level activities and system-level activities. Individual-level activities are those that are meant to have an impact on and benefit individual consumer/survivors. In contrast, system-level activities are more ecologically focused. These activities strive to have an impact on the human service system, the broader community, and social policy. While individual-level activities focus on supporting individuals directly (whether one-on-one or in groups), system-level activities work to create environments that are more supportive for people who have experienced mental health challenges.

Our next step was to organize the CSI activities and outcomes in the form of program logic models. A program logic model is a graphic illustration of what a program does and what it hopes to achieve, noting the rationale (or logic) between the two (Rush & Osborne, 1991). While initially our intent was to develop these logic models to gain a shared understanding of the similarities and differences of each participating CSI (i.e., a collective understanding of the program contexts), this exercise also proved useful in developing data-gathering tools.

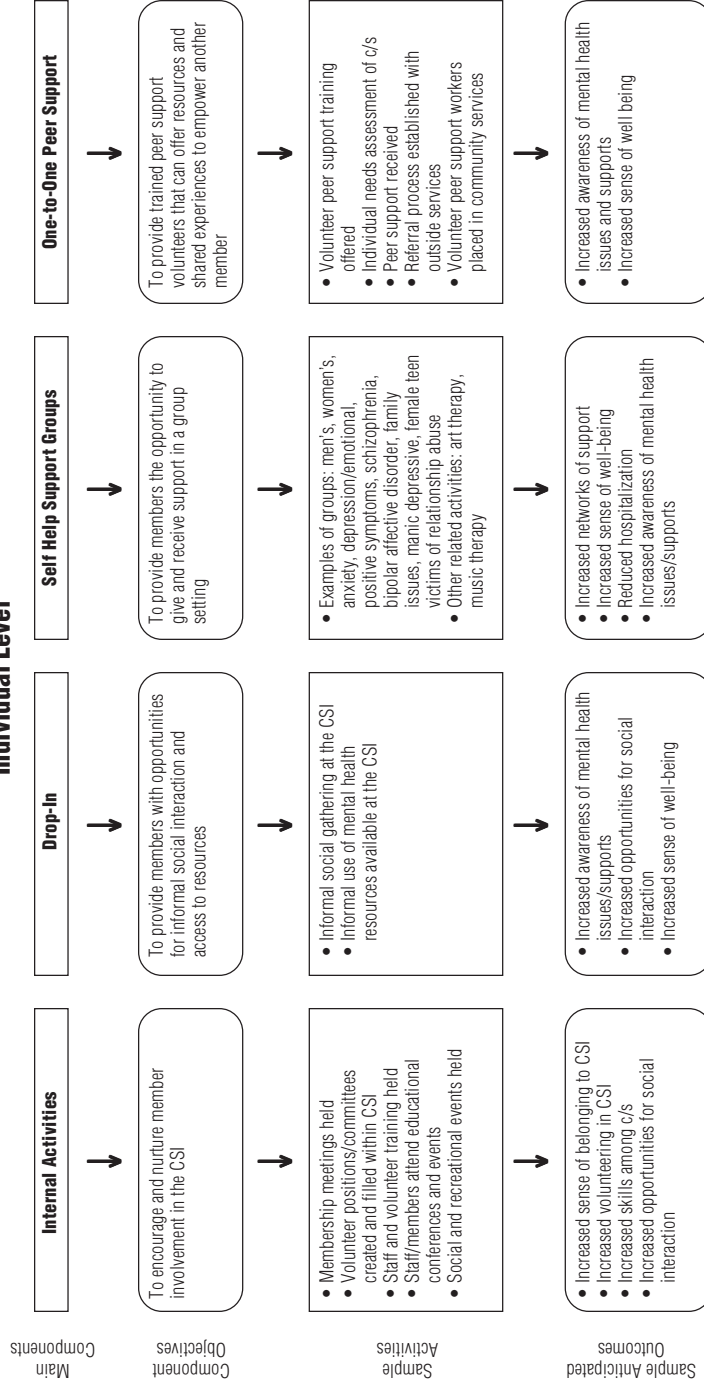
We as researchers developed one logic model for each site. Although each site had its own unique features, we attempted to visually show the similarities among sites as well. Most notable was that the system-level and individual-level distinction was common across all logic models, as were many of the main components (groupings of activities) within each of these two activity levels. We discussed and refined these program logic models during steering committee meetings throughout the early stages of the research study. Eventually there was agreement that each of the four logic models accurately represented the distinctive characteristics of each unique CSI, while the overall logic model captured the similarities across sites. A synthesis logic model is found in Figure 1.

With regard to *individual-level activities* there are four main components or categories of activities: (a) internal activities (activities seeking to encourage members to become meaningfully involved within the CSI, and that provide training opportunities toward this end), (b) drop-in (activities providing CSI members with informal opportunities for social interaction and access to mental health resources), (c) self-help groups (activities in which members give and receive support in a group setting), and (d) one-to-one peer support (activities in which trained peer support volunteers offer resources and share experiences to empower another member).

Figure 1
Synthesis Program Logic Model for Participating CSIs



Individual Level



Mission Statements

- CSI #1: To provide assistance to consumer/survivors of the mental health system of Waterloo region in their attempts to establish and maintain self-help mutual aid groups. The structure of the programs are such that practical and emotional support will be offered to consumer/survivors to enable the groups to grow toward total independence and function at an optimal level.
- CSI #2: We are a co-operative, self-help organization of people who have experienced mental health difficulties. Through a range of programs and activities, we strive to help ourselves and each other toward finding solutions to our problems, become more socially active, gain pride and respect, and increase our skills, employability and self-confidence. As a successful self-help group our goal is to be positive contributing members of both the mental health and business communities.
- CSI #3: To enable, encourage and empower the voice and participation of consumers of the mental health system in the Hamilton-Wentworth region.
- CSI #4: To advocate for the health and personal fulfillment of people who have used the mental health system. To establish a network of self-help groups throughout the Niagara region to provide consumer/survivors with the opportunities for friendship, social support, education and recreation.

While all sites had internal activities including membership meetings and staff/volunteer training, the remaining categories of individual-level activities varied across sites. For example, one site focused heavily on offering numerous self-help groups on wide-ranging issues; another preferred to use one-to-one peer support. Some sites offered regular and well-attended informal drop-in times for members, while other sites did not.

Organizing the individual-level activities and outcomes in these distinct yet similar logic models was helpful in creating a data-gathering instrument. We were interested in understanding not only individual-level outcomes over time, but how these outcomes related to overall participation and the amount and type of participation in local CSIs. Using the program logic models as a basis, we were able to develop a common tool to help us track how our study participants were active in each participating CSI.

With regard to *system-level activities*, we noticed four main components or categories of activities: (a) public education and relations (activities increasing awareness or changes in public opinions about mental health issues and people who experience mental health issues), (b) political advocacy (activities aimed at making changes in social policies and practices), (c) community planning and collaboration (activities bringing about changes in planning practices and existing services, as well as the creation of new supports and services), and (d) action research (activities gathering information to support the three previously mentioned system-level activities).

While sites differed with regards to the specific activities they focused on within each of these four categories, and while they each emphasized certain categories over others, they all had at least some activities within each category. These categories were similar to the primary system-level components found in other studies (Nelson, 1994; Tefft, 1987). These four system-level categories formed the basis of a tool that was used to track system-level activities and outcomes during the study. As with the individual-level tracking tool, this tool was common and applicable across all sites, yet flexible enough to identify the uniqueness of each site.

Choosing a Mixed Methods Design

While the social and health sciences have historically been dominated by quantitative methodology stemming from the paradigm of

logical positivism, there has been considerable growth in the use of qualitative methodology and the articulation of alternative paradigms of inquiry over the past 25 years (Denzin & Lincoln, 2000). Moreover, we assert that the field of program evaluation has led the way in carving out space for qualitative methodology and alternative paradigms (Greene, 2000; Guba & Lincoln, 1989; Patton, 2002). While some evaluation theorists adhere strongly to one paradigm and its assumptions about the nature of reality and what can be known (Lincoln & Guba, 2000), others adopt the approach of matching their research questions with the appropriate paradigm. Thus, if a researcher wants to know if a program leads to causal impacts on outcomes, a post-positivist paradigm emphasizing quantitative methodology is called for; but if one wants to know about people's experiences of a program, then a constructivist paradigm emphasizing qualitative methodology should be used.

Like Goering and Streiner (1996), we view quantitative and qualitative methodologies as complementary rather than as mutually exclusive. Our approach to evaluation is somewhat similar to that of Patton (2002), who emphasizes qualitative methodology, but borrows many of the concepts used in quantitative program evaluation, such as logic models, evaluability assessment, and evaluation of process and outcomes. We used a mixed method approach, using quantitative data primarily to address the questions of levels of activities and causal impacts and using qualitative data to address the questions of people's experiences and constructions of the CSIs. Moreover, we used quantitative and qualitative methods to examine both individual-level activities and impacts and system-level activities and impacts.

Individual Level

Quantitative. To examine the causal impacts of CSIs on new members, we used a non-equivalent comparison group design (Cook & Campbell, 1979), in which we compared new members who became active in the CSIs with a group of participants who were eligible to participate in but who were not active in CSIs. Using the CMHEI common protocol (Dewa et al., 2002), we gathered data on a wide range of demographic variables, self-reported diagnosis, service use (including hospitalization and emergency room utilization for the past nine months), and outcome measures with established reliability and validity and relevance to the outcome goals of the CSIs (personal empowerment, symptom distress, social support, quality of life,

and community integration). These measures are described in detail in forthcoming articles on this evaluation. The two groups were comparable at baseline on these variables.

Participants were interviewed at baseline (within 3 months of joining the CSIs for the active members), and 9-, 18-, and 36-month follow-up intervals. All participants were given an honorarium of \$15 for each of the first three interviews and \$25 for the 36-month interview. During the baseline interview, the interviewers discussed ways of keeping in touch with participants and asked for participants' consent to provide names of people who could assist in contacting them should they move and not leave a forwarding address or phone number. In the time between interviews, the interviewers used a variety of methods to keep in touch with participants, including contacting them by phone every two months, sending a thank-you card after each interview, and sending a birthday card and season's greetings card once a year. There was a 26% dropout rate from baseline (161 participants) to the 18-month follow-up (118 participants); those who dropped out were experiencing significantly more psychosocial and mental health problems than those who remained in the study.

To assess the level of CSI involvement for the CSI active participants, the interviewers phoned participants every two months after the baseline interview and asked them how many events/activities they had attended at the CSI and how much time they spent (in hours) in each activity, yielding two overall measures of the amount of participation in CSI activities (number of events and number of hours). At the 18-month interview, there were 61 participants who were active in the CSIs and 57 participants in the comparison group who were not active in the CSIs. Active members participated in a number of ways in the CSIs: (a) internal activities, such as membership meetings, social-recreational events, and committees (32%); (b) one-to-one peer support (25%); (c) drop-in (20%); (d) self-help groups (13%); and (e) external, system-level activities, including public education, community planning, advocacy, and action research (10%).

Qualitative. We also gathered qualitative data through interviews with a sub-sample of 15 CSI participants and 12 comparison group participants. These individuals were interviewed at the same intervals as the quantitative interviews and were remunerated the same

amounts for their participation. The semi-structured interviews covered topics such as past experiences with services and supports, personal life changes that occurred in the past nine months, and experiences with participation in the CSIs (for CSI members). These qualitative data were used to complement the quantitative data, by providing more depth regarding participants' life experiences and changes and providing insights on the qualities of CSIs that were important for the growth and change of participants who were active in the CSIs.

System Level

While individual-level activities focus on supporting individuals directly (whether one-to-one or in groups), system-level activities work to create environments that are more supportive for people who have experienced mental health challenges.

Quantitative. A system-level tracking log was adapted from a measure developed by Francisco, Paine, and Fawcett (1993) and based on the CSI program logic models. The purpose of using this tracking tool was to document the number and types of activities in which the CSIs engaged to create systemic change. For each system-level activity, staff completed information on the tracking log about the category of activity, date, brief description, target group, number of CSI staff and members involved, location, and resulting outcomes. The log was developed collaboratively with staff of the CSIs, and it enabled CSI staff to document information about each system-level activity during a given month.

Qualitative. We also gathered qualitative data to provide insight into the potential outcomes of system-level activities, as well as the nature of those activities. Toward this end, we conducted focus group interviews with CSI staff and members in each of the four CSIs and 13 individual interviews with service providers and health planners familiar with the CSIs. Overall we found two main types of system-level impacts of CSI: (a) changes in perceptions – perceptions about mental health or mental illness, perceptions about the lived experience of consumer/survivors, and perceptions about the perceived value of CSIs by service providers, policy-makers, or members of the general public; and (b) concrete changes – tangible changes in service-delivery practice, service planning, public policy, or funding allocations.

Summary

There are at least two reasons for gathering both quantitative and qualitative data in program evaluation. One reason is that these two types of data are complementary. Quantitative data in the context of a quasi-experimental design can suggest causal impacts, provide breadth by enabling data-gathering from a large number of participants, and yield precise estimates of the amount of program activity and impacts. Qualitative data can provide a deeper understanding of people's experiences, identify potential areas of impact that were previously unknown (as was the case with the system-level impacts), and uncover qualities of CSIs that participants found to be helpful in their process of recovery. A second reason is that these two approaches help to validate one another through a process known as triangulation (Creswell, 2003).

Emphasizing Dissemination and Action

The combination of academic expertise and experiential knowledge is the distinctive mark of participatory action research. The significance of this evaluation is that it posits evidence-based best practices while at the same time remaining true to the consumer/survivor values of empowerment, mutual aid, systemic advocacy, and personal growth and learning. Extending this paradigm to the dissemination strategy in itself arguably strengthens the traditional methods of knowledge transfer by targeting the communication of research results to a clearly delineated range of internal and external stakeholders. Wherever possible, the use of interactive techniques that speak directly to and are respectful of consumer/survivors is encouraged.

Characteristically in the past, the use of advocacy-charged and memoir-based personal narrative, whether in autobiographical literature (Capponi, 1992) or in film documentary (Basen & Sky, 1999), has been the means by which consumer/survivors most vividly depict and emote their paths to recovery. In that tradition, the study's findings will be illustrated through the production of a video by the Centre for Research and Education in partnership with OPDI. It will profile several of the CSIs and serve as a firsthand glimpse of their environment.

Furthering the dissemination among the consumer community, a series of regional information workshops were conducted through-

out the province; community members were also invited. The four participating CSIs who were the focus of the research took part in a wrap-forum in each of the participating communities. A presentation to the Mental Health Leads of the Ontario Ministry of Health and Long-Term Care (e.g., senior mental health planners in the province) was also conducted.

More traditional methods of dissemination include a project website dedicated to the study and its findings on the Centre's website, with links to the OPDI and the CSIs. A summary bulletin and fact sheet have been developed to create awareness among the general community and external stakeholders such as Mental Health Task Forces, District Health Councils, the Ontario Ministry of Health and Long-Term Care, and community mental health agencies. Academic journal articles that undergo a process of peer review will also be used for incremental progressive change that is attuned to the academic community.

CONCLUSION

In this article, we presented a framework for the evaluation of consumer/survivor-run organizations and illustrated how this framework was put into practice in a study of CSIs in Ontario. This evaluation was an important step forward for the consumer/survivor community in Ontario because, for the first time ever, consumers were active participants in a provincial mental health evaluation initiative. This helped to solidify the inclusion of consumers as important stakeholders and CSIs as an important component of the mental health system.

The framework that we used was comprehensive both in the conceptualization and design of the evaluation and in the process of conducting the evaluation. To fully capture the nature of consumer/survivor-run organizations, we assert that a mixed methods approach is needed to assess both processes and outcomes at both the individual and systems levels. As well, evaluators need to understand the values and concerns of CSIs and their members. In order to do this, evaluators must utilize highly participatory processes that are congruent with the values of consumer/survivor-run organizations. We have discovered that the researchers need to become immersed in the settings so as to develop the collaborative relationships and understanding of the unique nature of CSIs in order to make the

research process successful. It's not just what evaluators do that is important, but how they do it. We learned that the members of consumer/survivor-run organizations want a meaningful process, power over decision-making, and products that are useful to their organizations. To this end, we have described a number of strategies to fully engage consumers in the research process and to use the findings for dissemination and action. Moreover, consumers were an integral part of a project that demonstrates that self-help and peer support contribute to the recovery of individual consumers and to broader social and community change.

We believe that the evaluation framework that we employed is a good fit not just for the CSIs in Ontario, but also for other types of consumer/survivor-run organizations and initiatives. This framework could also be particularly useful for a number of other settings designed to be either an alternative or a complement to mainstream organizations. Alternative settings are developed and run by disadvantaged groups and have a strong emphasis on mutual support, egalitarian relationships, member participation, power-sharing, holism, and advocacy for social change (Reinharz, 1984). Examples of alternative settings include self-help/mutual aid groups and organizations, Independent Living Centres for people with disabilities, settings for women who have been abused or victimized, and alternative schools. These types of settings typically have a strong value base and both individual and system change activities and goals, which are qualities calling for the type of evaluation framework that we have articulated. While the framework that we have described may be particularly applicable to CSIs and other alternative settings, it may be more broadly applied to many other types of settings. Using participatory processes, logic models of program processes and outcomes, a combination of qualitative and quantitative methods, and a variety of dissemination and action strategies could prove valuable in any type of evaluation. While time-consuming, our experience with the evaluation of CSIs in Ontario shows that this evaluation framework is well worth the effort. Indeed, the partnership between professional researchers and consumers that we used challenges the traditional paradigm that has created a power imbalance between those asking the questions and those answering the questions and provides a new way of thinking about mental health research and knowledge transfer.

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REFERENCES

- Basen, G., & Sky, L. (1999). *Working like crazy*. Montreal: National Film Board of Canada and Skyworks Charitable Foundation.
- Bradley, J.E., Mayfield, M.V., Mehta, M.P., & Rukonge, A. (2002). Participatory evaluation of reproductive health care quality in developing countries. *Social Science and Medicine*, *55*, 269–282.
- Brandon, P.R. (1998). Stakeholder participation for the purpose of helping ensure evaluation validity: Bridging the gap between collaborative and non-collaborative evaluations. *American Journal of Evaluation*, *19*, 325–337.
- Campbell, J., & Leaver, J. (2003, March). *Emerging new practices in organized peer support*. Report from the meeting of the National Technical Assistance Center's National Experts, Alexandria, VA.
- Capponi, P. (1992). *Upstairs in the crazy house: The life of a psychiatric survivor*. Toronto: Penguin.
- Chamberlin, J. (1990). The ex-patients movement: Where we've been and where we're going. *Journal of Mind and Behavior*, *11*(4), 323–336.
- Cook, T.D., & Campbell, D.T. (1979). *Quasi-experimentation: Design and analysis issues for field settings*. Chicago: Rand McNally.
- Cousins, J.B., & Earl, L.M. (1986). The case for participatory evaluation. *Educational Evaluation and Policy Analysis*, *14*, 397–418.
- Creswell, J.W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.
- Denzin, N.K., & Lincoln, Y.S. (Eds.). (2000). *Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

- Dewa, C.S., Durbin, J., Wasylenki, D., Ochocka, J., Eastabrook, S., Boydell, K., & Goering, P. (2002). Considering a multisite study? How to take the leap and have a soft landing. *Journal of Community Psychology, 30*, 173–187.
- Fals-Borda, O., & Rahman, M.A. (1991). *Action and knowledge: Breaking the monopoly with participatory action-research*. New York: Apex Press.
- Fetterman, D.M. (2001). *Foundations of empowerment evaluation*. Thousand Oaks, CA: Sage.
- Fine, M., et al. (2003). Participatory action research: From within and beyond prison bars. In P.M. Camic, J.E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology* (pp. 173–198). Washington, DC: American Psychological Association.
- Fisher, P.A., & Ball, T.J. (2003). Tribal participatory research: Mechanisms of a collaborative model. *American Journal of Community Psychology, 32*, 207–216.
- Francisco, V.T., Paine, A.L., & Fawcett, S.B. (1993). A methodology for monitoring and evaluating community health coalitions. *Health Education Research Theory and Practice, 8*, 403–416.
- Frese, F.J., Stanley, J., Kress, K., & Vogel-Scibilia, S. (2001). Integrating evidence-based practices and the recovery model. *Psychiatric Services, 52*, 1462–1468.
- Galanter, M. (1988). Zealous self-help groups as adjuncts to psychiatric treatment: A study of Recovery Inc. *American Journal of Psychiatry, 145*, 1248–1253.
- Goering, P.N., & Streiner, D.L. (1996). Reconcilable differences: The marriage of qualitative and quantitative methods. *Canadian Journal of Psychiatry, 41*, 491–497.
- Greene, J.C. (2000). Understanding social programs through evaluation. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 981–999). Thousand Oaks, CA: Sage.
- Guba, E.G., & Lincoln, Y.S. (1989). *Fourth generation evaluation*. Newbury Park, CA: Sage.

- Lee, D.T. (1995). Professional underutilization of Recovery Inc. *Psychiatric Rehabilitation Journal*, 19, 63–70.
- Lincoln, Y.S., & Guba, E.G. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 163–188). Thousand Oaks, CA: Sage.
- McLean, A. (1995). Empowerment and the psychiatric consumer/ex-patient movement in the United States: Contradictions, crisis and change. *Social Science Medicine*, 40, 1053–1071.
- Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal*, 25, 134–141.
- 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. (2001). *Shifting the paradigm in community mental health: Towards empowerment and community*. Toronto: University of Toronto Press.
- Nelson, G., Ochocka, J., Griffin, K., & Lord, J. (1998). “Nothing about me, without me”: Participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors. *American Journal of Community Psychology*, 26, 881–912.
- Ochocka, J., Janzen, R., & Nelson, G. (2002). Sharing power and knowledge: Professional and mental health consumer/survivor researchers working together in a participatory action research project. *Psychiatric Rehabilitation Journal*, 25, 379–387.
- Omark, R.C. (1979). The dilemma of membership in Recovery Inc., a self-help ex-mental patients’ organization. *Psychological Reports*, 44, 1119–1125.
- 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 & Garvey.
- Patton, M.Q. (1997). *Utilization-focused evaluation* (3rd ed.). Thousand Oaks, CA: Sage.

- Patton, M.Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Powell, T.J. (1975). The use of self-help groups as supportive reference communities. *American Journal of Orthopsychiatry*, *45*, 756–764.
- 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.
- Reeve, P., Cornell, S., D'Costa, B., Janzen, R., & Ochocka, J. (2002). From our perspective: Consumer researchers speak about their experience in a community mental health research project. *Psychiatric Rehabilitation Journal*, *25*, 403–408.
- Reinharz, S. (1984). Alternative settings and social change. In K. Heller, R.H. Price, S. Reinharz, S. Riger, & A. Wandersman (Eds.), *Psychology and community change: Challenges of the future* (2nd ed., pp. 286–336). Homewood, IL: Dorsey Press.
- Rush, B., & Ogborne, A. (1991). Program logic models: Expanding their role and structure for program planning and evaluation. *Canadian Journal of Program Evaluation*, *6*(2), 93–105.
- Ryan, K., Green, J., Lincoln, Y., Mathison, S., & Mertens, D. (1998). Advantages and challenges of using inclusive evaluation approaches in evaluation practice. *American Journal of Program Evaluation*, *19*, 101–122.
- Segal, S.P., Silverman, C., & Temkin, T. (1993). Empowerment and self-help agency practice for people with mental disabilities. *Social Work*, *38*, 705–712.
- Shelton, R., & Rissmeyer, D. (1989). Involving consumers in the discharge process. *Psychosocial Rehabilitation Journal*, *12*(4), 19–28.
- Simmons, H. G. (1990). *Unbalanced: Mental health policy in Ontario, 1930–1989*. Toronto: Wall and Thompson.
- Stringer, E.T. (1996). *Action research: A handbook for practitioners*. Thousand Oaks, CA: Sage.

- Tan, C., Mowbray, C., & Foster, J. (1990). *Consumer-run drop-in center study: Technical report, executive summary*. Detroit: Michigan State University.
- Tefft, B. (1987). Advocacy coalitions as a vehicle for mental health system reform. In E.M. Bennett (Ed.), *Social intervention: Theory and practice* (pp. 155–185). Lewiston, NY: Edwin Mellen Press.
- 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.
- 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.

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