
Developing and Evaluating Community-Based Services Through Participatory Action Research: Two Case Examples

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KEY WORDS

- evaluation
- outcomes
- service development

Occupational therapy has a strong history of embracing concepts of client empowerment. However there is limited literature in the field on how to achieve empowerment, or on how to extend empowerment to the level of the community and social groups and services within it. This article discusses how concepts and strategies of participatory action research, an extension of empowerment theory, can be used to inform service development and evaluation in occupational therapy. The participatory action research approach is illustrated using two case examples of participatory action research programs for persons with chronic fatigue syndrome and individuals with autoimmune deficiency syndrome (AIDS). A critical analysis of the application of this approach to research and practice is provided. Finally, the paper identifies key principles of participatory action research that can be used to guide occupational therapy services and empower both individuals and communities.

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Over the past decade, the field of occupational therapy has undergone a rapid and deliberate evolution in the nature and complexity of problems that are addressed. An increasing number of occupational therapists have confronted the natural challenges involved in working with clients from traditionally oppressed groups, including those of diverse social, educational, economic, and cultural backgrounds (Bonder, Martin, & Miracle, 2002). Many of these clients face an escalating number of intrapersonal, interpersonal, and economic barriers to service within resource-challenged health care systems (Wells & Black, 2000). As such, the boundaries of the discipline's approach to practice have been forced open, and occupational therapists have been challenged to consider alternative approaches to practice. Current thinking emphasizes the importance of providing clients with the knowledge and resources to take control of their lives by equalizing power in the therapeutic relationship (Kielhofner, 2002; Law, Baptise, & Mills, 1995). Despite these trends, there has been limited discussion of how more adventuresome, community-based approaches to practice can be developed and studied through research.

Concepts and strategies of participatory action research, an extension of empowerment theory, is one such approach that can be used to transform occupational therapy clients into participant-researchers who organize themselves to develop, implement, and evaluate empowerment-oriented services not only for each other but also for the larger health care and social communities in which they interact. Participatory action research involves consumer participation, power, leadership, and knowledge generation in the development, implementation, and evaluation of services. According to Boyce and Lysack (2000), true participation involves a process of personal as well as social transformation in which decision

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making takes place in the hands of the consumer group and social conditions are thereby affected or changed. The participatory action research approach is typically associated with social action projects that emphasize the achievement of local, consumer-driven goals rather than the traditional aims of positivist science (e.g., scientist-driven, rational-deductivist approaches to research, and hypothesis testing according to highly controlled experimental research designs) (Bradbury & Reason, 2001). Therefore, much literature highlights differences between participatory action research approaches and more traditional outcomes studies that emphasize the prevailing standards of scientific rigor. In this paper, we argue that participatory action research can be profitably used in combination with conventional controlled research designs to support the creation of sound evidence for practice while still achieving the goals of consumer involvement and empowerment. We will discuss the history and definition of participatory action research, cover its application to occupational therapy, and utilize case examples to illustrate its unique strengths and limitations.

Participatory Action Research: Definition and History

Participatory action research combines multi-level investigation, education, and social action to generate sociopolitical awareness and mobilize participants to effect individual and larger systemic change (Brown & Tandon, 1983). By definition, participatory action research is driven by practical outcomes. The central tenet of participatory action research is that it begins with the problems and needs of community members, rather than with the researcher's conceptualization of those problems (Freire, 1970, 1993; Park, 1999). Another important aspect is that community members themselves engage in as many aspects of the process of research as possible (Park, 1999). This engagement not only includes defining what problems should be addressed, but also using the researcher as a consultant in making collective decisions about what research questions to raise, what methods of data collection to use, how the data should be analyzed, and how the outcomes should be presented (Park, 1999).

Methodologies involving participatory research emerged from the need for oppressed populations to empower themselves and improve their lives by acting to address the contextual issues (e.g., social, political, economic, environmental) that embed their experience of oppression. Best summarized by Freire (1970, 1993), the process of overcoming oppression must be known, initiated, accomplished, and reflected upon by the oppressed themselves through a process of dialogue with those in power. It

is only through this partnership between oppressors and oppressed that critical consciousness is achieved and eventual action can be undertaken (Freire, 1970, 1993).

The researcher's role in participatory action research is to become an intimate knower and participant within the community, joining as a partner by assuming various roles, such as community organizer, meeting facilitator, community advocate, activist, or resource person for technical or material aid (Park, 1999). Within a clinical context, a practitioner may traverse similar roles, always allowing the client to dictate the essential elements of the therapy process. Similarly, participants in research may undertake multiple and perhaps unexpected roles and relationships, including leadership roles involving other participants, academic researchers, health care agency representatives, community based organizations, and public officials. This flexibility and careful use of power in defining multiple roles that can be assumed by both participants and researchers can be applied to occupational therapy practice in that they define the necessary requirements for legitimate empowerment within the therapeutic relationship.

Participatory Action Research and Health Care. For individuals with disabilities, participatory action research can be defined as a process by which activities are organized by groups of persons who have disabilities in partnership with others who do not, to increase their ability to influence social conditions, and improve their own lived experiences with disability (Boyce & Lysack, 2000). This approach to research originated in the 1970s, as scholars from a number of disciplines (e.g., sociology, anthropology, education, theology, and psychology) were becoming increasingly concerned about life conditions, which appeared unbearable, in developing communities low in economic and health care resources throughout the world (Fals-Borda, 1985; Fals-Borda & Rahman, 1991; Park, 1999).

In the domains of health and disability, two traditions of participatory, community-based research in the international health and development context were initiated in that same decade (Boyce & Lysack, 2000; David, Zakus, & Lysack, 1998): (1) the primary health care campaign, "Health for All by the Year 2000," introduced in 1978 by the World Health Organization (World Health Organization [WHO], 1978); and (2) the community-based rehabilitation movement, which emerged with the primary health care campaign in recognition that rehabilitation was a key aspect of the campaign toward community involvement in health care (WHO, 1981). These movements were developed from local grassroots initiatives that attempted to address the needs of individuals with disabilities in underserved communities by delivering "low-tech" rehabilitation services efficiently (Boyce & Lysack).

However, many of these studies engendered passivity among participants, and though they embraced concepts of community participation in theory, in practice many resorted to the use of professionally-initiated strategies that failed to fully include the voices of community members in program planning and implementation (Boyce & Lysack). To answer the limitations of these earlier movements, a community development model was proposed in the late 1980s and early 1990s (Boyce & Lysack). The goal of the community-based rehabilitation movement then shifted toward improving the everyday lives of individuals with disabilities and sustaining these improvements locally through social inclusion, political equality, and the translation of clinical and technological knowledge into relevant health care information and self-help skills (Boyce & Lysack, 2000; Labonte, 1994; Park, 1999).

The Methods of Participatory Action Research

Methodological approaches to participatory action research are multidimensional, but generally involve six steps, which are depicted in Figure 1 and described below.

Step 1. Delineating the Problem. An initial and large aspect of the process of participatory action research involves careful documentation of the concrete and specific ways people view a problem as affecting their lives. Participants should achieve an understanding of the ways in which dominant social structures and ideologies produce or contribute to the problems they experience in daily life (Freire, 1970, 1993; Park, 1999).

Step 2. Choosing Action. The next step of the process involves participants choosing an action-oriented solution (Park, 1999), such as a peer-directed program of services or an advocacy effort. Depending on the context, choosing or implementing a solution may require systematic deliberations, political negotiations, or even struggles with existing power structures.

Step 3. Design and Assessment. After the favored approach has been chosen, participants, with assistance from the researcher, then engage in choosing the research design, approach to data collection, and measures. Research designs and approaches to measurement may vary tremendously according to the alternative forms of knowledge embraced (Park, 1999). Critical is that these methods match the agendas and preferred ways of knowing of the participants.

Step 4. Engaging in Action. Action in this case can take on many meanings, including, for example, implementing a program of occupational therapy services, advocacy efforts to change insurance legislation, or promoting organization-

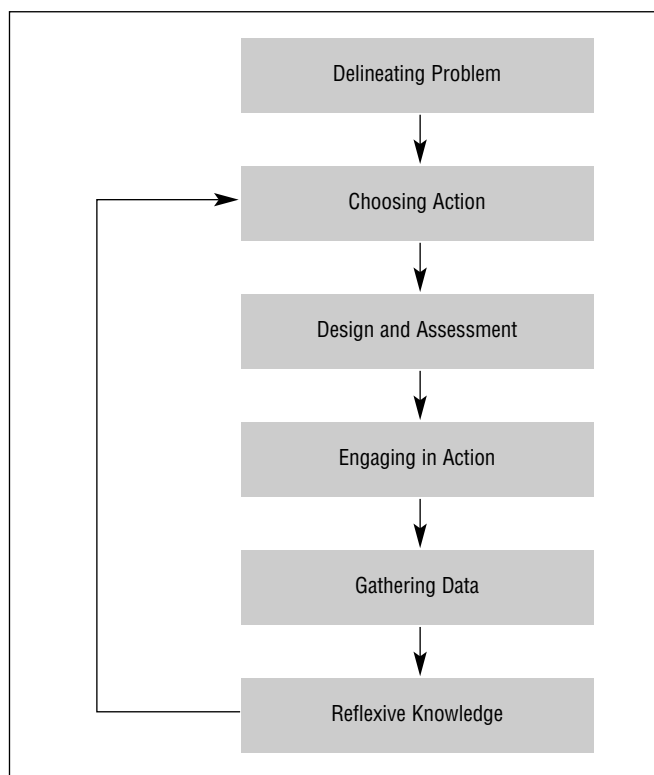


Figure 1. The Methods of Participatory Action Research.

al change in health care. Participants will benefit most from this stage in the research if they are fully engaged in, if not in control of, this action.

Step 5. Data Collection. Depending on their level of resources, participants are then encouraged to assume control over data collection, in logistical consultation with the researcher.

Step 6. Reflexive Knowledge. In the final step, participants and researchers reflect on the action process and the results they have achieved. Processes of mutual reflection between researchers and participants can interact to fuel an ongoing process of refinement of action steps (e.g., services). The final step should stimulate a reflection-action-reflection cycle (Freire, 1970, 1993) in which ongoing understanding of new problems and action to address those problems is mediated by the production of knowledge (Park, 1999). A process of true empowerment should occur in which participants become increasingly able to independently sustain the research effort to address new needs and barriers they may be confronting, without professional resources.

Participatory Action Research and Clinical Outcomes

In the context of outcomes research that seeks to provide evidence about services, participatory action research can be used as a way to assure that consumers' voices are integrated

into and shape the scientific process. The goals of integrating participatory action research into outcomes research are: (1) to develop and test strategies that empower consumers as individuals and groups, and (2) to work toward changing systems to remove barriers and inequities. Examples that follow in this paper illustrate two different models of using participatory action research as a framework for undertaking large multi-year federally funded studies. Each project addresses an underserved disability group that has faced multiple internal and socioenvironmental barriers to independent living and illustrates how participatory action research can be used in the development of new services and documentation of their outcomes. The first project addresses independent living for persons with chronic fatigue syndrome and the second aims to employ individuals with human immunodeficiency virus (HIV) or autoimmune deficiency syndrome (AIDS).

The Chronic Fatigue Syndrome Empowerment Project

Chronic fatigue syndrome is a prevalent (Jason et al., 1999) and highly debilitating condition characterized by 6 or more months of medically and psychiatrically unexplained, persistent fatigue and four or more cognitive and physical symptoms that persist or relapse concurrently with the fatigue (Fukuda et al., 1994). Chronic fatigue syndrome has been legitimated as a medically determinable condition by the social security administration (Social Security Ruling 99-2p), yet many individuals with chronic fatigue syndrome report negative experiences with service providers characterized by outright disbelief, lack of understanding of chronic fatigue syndrome, over-emphasis upon psychological or psychosocial explanations, and a general lack of responsiveness or treatment planning (Anderson & Ferrans, 1997; Banks & Prior, 2001; Taylor, Friedberg, & Jason, 2001). Perhaps as a result of this tension, persons with chronic fatigue syndrome report a lack of social and public support and tend to under-utilize rehabilitative services and community-based resources (Jason, Ferrari, Taylor, Slavich, & Stenzel, 1996).

The Chronic Fatigue Syndrome Empowerment Project (Taylor & Jason, 2002) is a federally funded study designed to develop and evaluate a consumer-driven program for individuals with chronic fatigue syndrome. It was designed to provide individuals with chronic fatigue syndrome an opportunity to learn self-advocacy skills and improve quality of life, functional capacity, coping skills, and resource acquisition through both group and individualized peer counseling. A randomized, delayed-treatment control group design was used to evaluate the impact of the pro-

gram. The project is currently in its final year of implementation.

Planning Services. Individuals in the chronic fatigue syndrome community, as well as members of the staff of the center for independent living, participated extensively during the initial steps of project planning. Their involvement in planning the services influenced the structure (e.g., the need for both group and one-on-one contact), pacing (e.g., biweekly groups rather than weekly groups), and location of the program of services (e.g., need for a setting to accommodate chemical and other sensitivities). Other aspects of the project resulting from participatory methods were the inclusion of personalized transportation to and from the program site to maximize the opportunity for even the most disabled individuals with chronic fatigue syndrome to participate. Finally, the participatory process identified the importance of providing reasonable access to key resources, such as personal assistance with activities of daily living, housekeeping, low-cost accessible transportation, subsidized housing, affordable legal assistance, assistance with gas and electricity, and vocational rehabilitation services.

Staff of the center for independent living advised on how to position the program within the center to best facilitate independent living skills. They also shaped the component of the program designed to transfer knowledge and expertise about chronic fatigue syndrome from the peer counselors and program participants to the other staff members at the center for independent living. This aspect of the project was designed to assure that the center for independent living sustains the program in the absence of support from the researchers.

Implementing Services. Participants learned about the program through newspaper and media advertisements, local physicians, and through local self-help organizations dedicated to individuals with chronic fatigue syndrome. They referred themselves to the program and underwent informed consent by receiving and signing a consent form, having procedures explained by telephone, and returning the form in the mail. Diagnosis of chronic fatigue syndrome was verified through an initial interview and review of medical records, and participants with confirmed chronic fatigue syndrome were randomly assigned to either an immediate or a delayed program group. Participants in the delayed group waited a year, undergoing only assessments, while the immediate program participants received the program.

The program itself is divided into two phases: a group phase consisting of 4 months of peer facilitated illness management groups, and 7 months of a one-on-one peer counseling phase. The program involves five key components, each of which exemplifies a participatory approach to

practice: client-driven goal setting and self monitoring, an educational curriculum designed and developed by the clients, peer counseling, self-advocacy training, and access to a personal resource fund. The empowerment of participants is multifaceted and involves a learning process. Participants increasingly recognize that, collectively, they share a tremendous amount of power and experiential knowledge. This process is consistent with the reflection-action-reflection cycle that sustains the initial research effort past the initial action stage. This cycle is mediated by the production and exchange of key knowledge between researchers and participants (Park, 1999).

Goal Setting. The Chronic Fatigue Syndrome Empowerment Project employed a client-driven approach to goal setting and goal attainment developed by Balcazar, Keys, and Garate-Serafini (1995). Clients selected their own goals individually, working with peers and with the support of project staff. Clients rated the relative importance of each of their goals, identified realistic steps to take in order to achieve those goals, and self-monitored their own goal attainment. This process allowed the participants to determine their own course of services and select their own resources to support goal attainment.

Group Phase: Peer Counseling. In accord with the empowerment-oriented principles of participatory action research, a peer counselor with chronic fatigue syndrome and the first author conducted one 2-hour focus group with participants as the first of eight peer counseling sessions. Focus groups are frequently used in participatory action research to inform a variety of practices, including needs assessment, program development, and program evaluation. During this first focus group, participants helped identify 12 educational topics relevant to illness management and then voted on the seven that they perceived as most relevant to their needs and goals, thus determining the content of the group component of the program.

After selecting these topics, participants were then encouraged to identify areas of more specialized focus within each of these seven major themes according to their individualized needs and goals for the program. Participants with particular experience or expertise in any one of these areas were encouraged to prepare a presentation on that area for the group session dedicated to that theme, again consistent with the ideology of participatory action research and peer-facilitated interventions fuelling this project. As a consequence, the peer counselors or participants often served as presenters in the group. This process promoted maximal participation, a key principle of participatory action research (Bradbury & Reason, 2001).

One-on-One Phase: Self Advocacy Training. Participants were provided with one-on-one peer counseling and self-

advocacy training to create their own linkages to supportive services during this second phase of the project. This component allowed each participant to determine the services he or she would receive during the second phase of the program. This element was augmented by the fact that resource funds were provided to each participant to support the purchase of other services and resources needed to accomplish personal goals. By deciding how to use their funds, clients were able, once again, to shape their own services.

Evaluating Services. Individuals with chronic fatigue syndrome who assisted with project planning also played a key role in advising the researchers regarding the relevant outcomes to evaluate the effectiveness of the program within the framework of the study design. They reviewed the assessments, identified which outcomes were of greatest importance, and made suggestions about how interviews should be administered. The researchers employed both quantitative and qualitative methods to evaluate the impact of the program on outcomes. The following outcomes were measured quantitatively using valid and reliable measures: fatigue and symptom severity; quality of life; functional capacity; service utilization; resource acquisition; and coping. Goal attainment, empowerment, sense of community, self-advocacy, and grasp of the independent living philosophy were measured qualitatively using a modification of the Goal Attainment Scale (Balcazar et al., 1995) and the content analysis of open ended questions. An analysis of two of the outcomes thus far, quality of life as measured by the Quality of Life Index (Ferrans & Powers, 1992) and symptom severity as measured by the Symptom Severity Index (Jason et al., 1997) has revealed that the program had a positive impact on both outcomes. Ongoing feedback about both the content and process of implementing the program was also gathered from the participants in writing, using an End-of-Group Reflections form following each group session, and by telephone interview, using a One-on-One Phase Feedback Form following the one-on-one phase. This feedback was incorporated into the continued implementation of the project.

The Employment Options Program for People With AIDS

New combination drug therapies that became available in the 1990s dramatically decreased mortality and transformed AIDS into a chronic disabling condition. Because of this rapid transition, many of the agencies that served persons with AIDS had to rethink their services. A community-based health center serving the gay and lesbian population in a large city inquired whether occupational therapy could provide services for an increasing number of their

clients with AIDS who were expressing interest in returning to work but were also identifying a need for support. Some of these clients had previously developed serious symptoms and received the recommendation to leave their jobs and go on private or public disability to assure adequate medical coverage until their deaths. Other clients, who were unemployed when diagnosed with AIDS, had previously not been encouraged to pursue employment, given their prognosis. With the new pharmacological treatments, these clients had experienced improvements in their health and function that made it possible for them to consider working.

Collaboration with the community health center resulted in Employment Options, a program designed to provide occupational therapy services to persons living with AIDS to enable them to achieve employment. This 3-year project used participatory action research as a means of continuously improving the program so that a model of consumer-driven service evolved. In contrast to studies that seek control by standardizing the intervention and comparing different service conditions, this project used a strategy of continuous service development and improvement. As information was gathered, it was analyzed and applied to enhance services.

Planning the Project. Consumers were identified through a community health center, other public and private community agencies, residential facilities and outpatient medical programs that served persons with AIDS. Potential participants learned about the study from written materials, caseworkers, and other health providers and referred themselves to the project. When potential participants contacted the research group, the program and study were explained and informed consent was obtained. Criteria for admission to the study were a diagnosis of AIDS and an expressed desire to achieve employment.

Initially a consumer survey was conducted to determine interest in such a program. A pilot program was funded and a program was developed with consumer input about the kind of content that was wished for. During the pilot survey, consumers collaborated on identifying their own needs and desires and thus shaped content of the program. When the proposal was prepared for the larger study, the pilot intervention formed the core of the proposed program. Additional elements were added based on feedback from clients in the pilot and from case managers who worked with potential future clients.

Implementing the Project. The program of services, which was based on the Model of Human Occupation (Kielhofner, 2002), addressed motivational, life pattern, performance capacity, and environmental factors that influence successful employment. There were three components

of the program. A group component was administered by two occupational therapists and peer mentors. The groups were focused on educating and supporting clients to seek and obtain employment. During the same program period, an individual (one-on-one) component was administered by the occupational therapists. This component focused on developing self-awareness and building self-advocacy skills for use in the workplace. An environmental component centered on facilitating adjustment in the workplace, obtaining accommodation and advocacy for resources and rights (second-order change).

Since the program was implemented with small cohorts of clients, each successive cohort received services that had been modified based on experiences with and the perspectives of the previous cohort. The results of changed services were then evaluated with the new cohort and those findings shaped the next cohort's services.

A key method of data collection was in-depth interviewing by the occupational therapists at baseline upon entry to the program and during the program and at critical points. The first semistructured interview focused on the client's personal, work and illness history, along with future expectations for working. Subsequent interviews focused on perceptions of personal progress and experiences in the program, and concerns and issues encountered during placement in volunteer work or jobs or both. In addition, clients participated in data collection by engaging in self-assessment and evaluated the goals and content of their individualized services, filling out forms at the end of groups and at the end of series of group sessions, and participating in focus groups to comment on the program. Feedback about the program was also gathered through spontaneous discussions between the therapists and participants about program components as each cohort of persons progressed through the program. More detailed information about these methods is available from the second author.

An important component of the participatory action research approach in this project was how all members of the project worked together. Project staff and clients functioned in a manner that parallels Reason's (1988) description of a co-operative inquiry group in which people "work together as co-researchers in exploring and changing their world" (p. 18). Basic to such a team is authentic collaboration that aims to break down the traditional distinction between the roles of researcher and participant and to produce valid findings that have the "quality of being well founded on experience" (Heron, 1988). The two occupational therapists from the university and the vocational placement specialist from the university, whose primary roles were to deliver services, were included in service delivery and data collection as integral partners in the research

process. Their roles included collecting much of the data from clients, participating in ongoing data analysis and incorporation of findings into ongoing service development and modification, and participating in analysis and preparation of papers for publication. Client involvement varied but included activities such as providing validation of findings and interpretation of data for the researchers that pertained to their own experiences. Moreover, clients participated in discussions with the researchers of how findings could be translated into program revision.

As an example of how findings shaped ongoing program implementation, we discovered that having AIDS was not the central life issue for many of these clients. Although a common denominator for all clients who came to the program was that they had AIDS, both the role that AIDS played in their life situations and the extent to which it was the major impairment or challenge affecting performance varied. As is becoming increasingly common among people with AIDS, many clients had other major limitations including substance abuse, mental health problems, domestic violence, homelessness and criminal histories. This meant, for example, that staff had to become more aware of how to support those who were recovering from substance abuse, how to help clients find relevant resources and services for issues beyond AIDS, and to take into consideration a variety of impairments and challenges unique to each client.

Some clients who came to the program with the intention of working discovered that, for them, working was not a feasible or desirable goal. Many factors such as ongoing health problems, finances, and personal relationships led these clients to redefine their needs—desires from working to other productive aims such as volunteering. This produced an initial dilemma since the project was funded under a program whose aims were to help clients achieve employment. Nevertheless, the program was altered so that when clients decided not to pursue employment, they could continue to receive services to support the desired outcome.

A major component of the planned program was to work with employers to identify jobs where clients could be “placed.” However, it turned out that most clients did not want to be placed by the program. Being referred by a program serving persons with AIDS would effectively disclose the AIDS status of client. Consequently, most clients preferred to find work on their own in order to preserve the confidentiality of their diagnosis. Instead of placement services, they wanted support for job search strategies. Consequently, it was necessary to retool this part of the program.

The program design involved moving through four stages of services of a fixed length (i.e., (1) group and indi-

vidual therapy; (2) placement in job training, volunteer work, or temporary employment; (3) placement in gainful employment; and (4) long-term follow-up). The original design proved to be too rigid to serve most client needs. Instead, the program had to be modified to accommodate clients moving through phases at quite different rates and to allow for clients to move back and forth between phases and to take “leave” from the program as changes in health status and life circumstances dictated. Although some clients did proceed through the program more or less as preplanned, many clients proceeded in quite individual ways. Thus the planned program of services had to be extremely flexible to “individualize” services.

As the examples indicate, the program underwent substantial revision from how it was initially conceptualized. Thus, over the course of project implementation, it was possible to continuously improve the program to fit the needs of clients. Moreover, as elements of the program were altered, it was possible to see whether the alterations were working.

Evaluating the Project. Since this project focused on continuous development, much of the evaluation process occurred during program implementation as just discussed. However, the study also examined client outcomes and factors related to those outcomes. Some of the key questions that guided how the program was evaluated were: *What kinds of changes in client performance are achieved in the program? What changes in client characteristics are most predictive of successful employment? What accounts for clients who find the program helpful and benefit and those who do not? What were the outcomes of the program and how did clients view them?*

These questions focused the ultimate evaluation on client perspectives. Outcomes data were collected through follow-up interviews 6, 12, 18, and 24 months after they enrolled in which clients were asked about what factors accounted for their outcomes as well as how they viewed their outcomes. The central outcome was that the program was successful in assisting 67% of program completers in either achieving employment, returning to school, or beginning a volunteer or other internship position. Individuals with a history of mental illness and those with an illness narrative indicating positive progression (i.e., a progressive narrative slope) were more likely to successfully complete the program than those without. Once again, we sought to involve participants (clients and service providers) as key persons in the process of collecting and analyzing data and interpreting findings. For example, as already noted, some clients decided on an alternative to paid employment. While the project was originally designed to achieve employment, we decided with client input that other

accomplishments such as improving quality of life through volunteer work or other alternatives to employment should be considered positive outcomes.

Strengths of Participatory Action Research

Participatory action research has been described as having wide health and social benefits for individuals with disabilities. A review (David et al., 1998) described benefits as including a heightened sense of responsibility for health on the part of participants, an accompanying gain in power achieved through the acquisition of new skills, knowledge, and control over resources, more equitable relationships between participants and researchers, lower health care costs and greater use of indigenous expertise, increased likelihood for a match between community needs and resources, decreased feelings of alienation among participants, and the potential for greater diffusion of health knowledge in the community. Participants and community agencies involved in both projects described herein have reported a number of these benefits, similar to numerous other studies using participatory approaches to research (Reason & Bradbury, 2001).

Challenges and Tensions in Participatory Action Research

Though the theoretical foundations for participatory action research may appear sound and even ideal in terms of occupational therapy's mission to empower clients and alter environmental contexts (Kielhofner, 2002), the actual conduct of this adventuresome approach to research is not without challenges and limitations (Boyce & Lysack, 2000; David et al., 1998; Park, 1999). Participatory approaches to research are characterized by the investment and participation of multiple stakeholder groups (e.g., persons with disabilities, partners–family members, community agency staff, health care professionals, and researchers). One of the central challenges in conducting participatory action research involves the variegated and often contrasting agendas (independence, support, management, accountability, resource development) and modes of operation (self-help, advocacy, service, awareness raising, training, and data collection) of these stakeholders (Boyce & Lysack, 2000; David et al., 1998).

For example, two community-based organizations with somewhat contrasting agendas and worldviews on disability were involved in the Chronic Fatigue Syndrome Empowerment Project: a local self-help organization and a center for independent living. Both shared the agenda of advocating for resource acquisition for participants in the

program. However, the self-help organization tended to support a more traditional medical model approach to understanding the syndrome, emphasizing the unique needs of individuals with this condition that differentiate them from individuals with other types of disabilities, while the center for independent living favored a cross-disabilities perspective that embraced similarities between individuals with different disabilities and supported concepts of independence and civil rights over medically based knowledge and services. Consequently, the resulting program attempted to incorporate both perspectives, as well as the perspectives of the participants themselves, with varying success depending upon the stakeholder considered. Ultimately, since the focus of the program was empowerment and the integration of individuals with chronic fatigue syndrome into centers for independent living, the intervention emphasized client engagement in goal setting, community-based resource acquisition, and advocacy over more traditional medical services.

Associated with the challenge of multiple stakeholders are key decisions and complexities involved in the allocation of power among these stakeholders. Ideally, participatory research places complete power and responsibility for research development, implementation, and evaluation in the hands of consumers, and control of the process should be located locally within the community (Freire, 1970, 1993). However, practical and logistical challenges can interfere with the level of control that participants actually achieve. For example, the tasks of participatory research can involve high levels of participant burden, including personal energy, new knowledge acquisition, time, space–housing, and considerable financial resources. In some cases, achieving active consumer investment and identifying community leaders willing to buy into the research process can be a difficult challenge, particularly when participants have impairments that limit their energy or material resources (Boyce & Lysack, 2000). Obtaining funding and adhering to agency guidelines and timelines can be equally challenging. As a result, participants and community groups may attempt to resist or relinquish control, or they may find themselves under the partial, if not complete control of governmental agencies, university or health care systems, or private grant foundations due to the need for financial resources. Park (1999) described this dilemma succinctly, “the very state of deprivation, which produces a kind of helplessness, tends to militate against [participant-controlled action] (p. 144).”

It would be difficult and perhaps counter to the ideology of true participation if researchers were to attempt to quantify and select participants based on personal characteristics (e.g., physical energy), skills, or resources necessary

to sustain engagement in action over time. Thus, the actual process of participatory research often more realistically involves a careful sharing and reciprocal exchange of power between stakeholder groups and researchers in order to accomplish project aims. This can necessarily compromise the amount of power held by participants. Labonte (1994) described the ideal treatment of power in the participatory relationship as a dialectical relationship in which power is simultaneously given and taken by researchers. However, a more realistic scenario is that some clients lacking in resources may request that the researchers assume more power in one area of the research process (e.g., data collection) provided that they can retain power in other areas (e.g., selecting the course of action). This was the case in the Chronic Fatigue Syndrome Empowerment Project. The peer counselors and participants assumed control over the intervention, but lack of energy required the peer counselors to rely on the researchers for assistance with aspects of data collection.

In addition to these issues, contextual variables can either facilitate or challenge the conduct of participatory action research. According to David, Zakus, and Lysack (1998), the environmental context for participatory work must include a number of features, including a stable organization and structure within which participants can come together to engage in action. Moreover, the context should embrace a political climate that accepts and supports both the ideological and pragmatic aspects of participatory work at all stages of the process (e.g., program development, implementation, and evaluation). The context should also embrace local circumstances, aspirations, and needs in terms of its policies and decisions regarding resource allocation, and it should accept decentralization and local authority for decision making on issues of policy and resource allocation (David et al., 1998). Realistically, a context that meets all of these requirements can be difficult to find, thus leaving abundant work for the researchers and participant-researchers in the realms of advocacy, dissemination, and public policy work.

Summary

In summary, the Chronic Fatigue Syndrome Empowerment Project and the Employment Options Project each used participatory action research approaches in different ways to create and sustain new models of service and evidence about their outcomes. Each program illustrated three major principles of participatory action research. First, people with disabilities, those involved in service delivery, and the community-based organizations associated with the projects identified the needs and problems of focus within

their communities (Jason, Ferrari, Taylor, Slavich, & Stenzel, 1996). This assured that the services and the criteria by which they were judged were consumer driven and relevant. Second, the services that were developed went beyond the more traditional focus on remediation of problems. Both projects drew upon participant knowledge and assumed a strengths-based approach in which participants were encouraged to recognize, use, and build upon their existing resources to accomplish their goals. Third, former partitions between traditional roles (e.g., researcher, consumer, service provider) were eliminated. As a result, all those involved broadened their skills and knowledge. This reflexivity is a key component of the therapeutic relationship in any participatory approach (Bradbury & Reason, 2001).

Through the critical consciousness generated by their active participation in research and service provision, a new model of occupational therapy services might be built in which community-based centers of participatory action research are created. These centers might empower clients, practitioners, and center administrators to not only define and address problems at the impairment level, but also to identify and mobilize to change the social and contextual circumstances exacerbating the problem (e.g., social isolation, financial stress, inaccessible housing, unaffordable health care, lack of disability insurance, unemployment, and public accessibility problems). This article describes two potential contexts for the sustenance of this vision of empowerment: centers for independent living and community-based residential care facilities, both of which have incorporated occupational therapy practitioners to assist clients in the process of change through community participation. As current trends indicate that our nation and the world are facing escalating rates of impairment coupled with high rates of poverty, unemployment, and a rapidly increasing aging population (Kinsella & Velkoff, 2001), similar practice frameworks will be increasingly important and necessary to develop. The likelihood of their success will depend upon the strength of the voices of the consumers that embrace them.▲

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