

## ARTICLES

# Developing and Systematically Implementing Participatory Action Research

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Participatory Action Research (PAR) is a collaborative approach to conducting research that recently emerged as a paradigm for bridging science and clinical practice. The key characteristic of this approach—collaboration between consumers and researchers—often increases the relevance of research while maintaining the standards of scientific rigor. Although PAR is receiving increased attention from researchers and consumers in social science and public health, it has not been implemented widely. Some of the reasons for a limited application of PAR in the field include lack of knowledge about PAR and strategies for its implementation. This article defines PAR, provides an overview of the characteristics of this approach, and discusses 4 elements for systematic incorporation of the PAR approach into the research process. The elements are (1) participant selection and recruitment, (2) role and relationship clarification for researchers and participants, (3) research team education, and (4) management and support.

**Key Words:** Consumer participation; Cooperative behavior; Partnership practice; Rehabilitation.

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**I**N THE LAST 3 DECADES, Participatory Action Research (PAR) has emerged as a new paradigm for conducting research in the social sciences.<sup>1-6</sup> The key characteristic of PAR—collaboration between participants and researchers—often increases relevance of research and improves its social validity,<sup>7,8</sup> while maintaining the standards of scientific rigor. Although only a few studies provide empirical documentation of PAR advantages,<sup>9</sup> some benefits of involving participants may include development of more pertinent research questions, user-friendly instruments, acceptable interventions, thorough data analyses, and effective dissemination strategies.<sup>10-12</sup> Using the PAR approach could improve the credibility and validity of research,<sup>13</sup> increase utilization and sustainability of research-based programs,<sup>14</sup> and enhance empowerment of consumers.<sup>15</sup>

Despite the benefits of PAR and the growing literature related to it, the methods of actual applications are rather vague.<sup>1,16</sup> Reports of how PAR has been implemented are

neither presented in terms of specific and observable behaviors of both researchers and participants nor in terms of technologic interventions.<sup>17,18</sup> A lack of defined procedures makes PAR difficult to apply systematically and replicate. In contrast, a well-described set of procedures for PAR implementation could improve replication, integration into research efforts, and training. However, because of the large number and diversity of research projects incorporating PAR, a detailed description of all procedures required for PAR application is beyond the scope of this article. Our purpose is to define PAR, describe 4 key elements for PAR implementation, and offer suggestions for future research related to PAR.

## DEFINITION OF PAR

The term *participatory action research* was coined by Hall<sup>4(p7)</sup> to describe “an integrated activity that combines social investigation, educational work, and action.” It is important to note that this approach was intended to be a research activity—a systematic study of a situation that resulted in the production of knowledge.<sup>19</sup> Although subsequent authors often cite Hall, they have defined PAR in a variety of ways. For example, Whyte<sup>14</sup> has emphasized the applied aspect of PAR by writing that its goal is to seek information and ideas to solve problems of an organization. In his conceptual framework, the agents of change are not researchers but members of the organization who are actively engaged in the research process. In contrast, Maguire<sup>20</sup> has stressed the aspect of social change that is accomplished when researchers and the oppressed collaborate. Reason<sup>21(p1)</sup> has defined PAR as an emerging paradigm of cooperative experimental inquiry in which research is conducted “*with and for* people rather than *on* people.” Greenwood et al<sup>22</sup> have stated that some of the reasons for the different definitions may involve the diversity of fields in which PAR has been applied, the diversity of research questions and participants, and the scope of PAR.

Despite the differences in PAR definitions and applications, there is more convergence than divergence among participatory projects. The commonalities include (1) meaningful consumer involvement in all phases of the research process, (2) power sharing between researchers and consumers, (3) mutual respect for the different provinces of knowledge that the team members have, (4) bidirectional education of researchers and consumers, (5) conversion of results of research into new policy, programmatic, or social initiatives, and (6) the fact that PAR stands in stark contrast to the traditional standard for conducting research in which participants are treated as passive objects of study.<sup>5,23-25</sup> Additionally, the common element of various PAR projects is the fact that PAR is regarded as an orientation to research, not as a method.<sup>26</sup> Thus, there is no 1 way to implement PAR. Graves<sup>10</sup> and Turnbull et al<sup>9</sup> have emphasized that PAR is a collaborative approach to conducting research that can be used in both qualitative and quantitative research.

PAR literature spans the social sciences and examines various issues. For example, PAR has been used in anthropology,<sup>27</sup> applied behavior analysis,<sup>6</sup> business,<sup>28</sup> community psychology,<sup>29</sup> disability research,<sup>9</sup> education,<sup>3</sup> epidemiology,<sup>30</sup> and health promotion.<sup>31</sup> Issues addressed in participatory research

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include improving community health, assessing strengths and struggles of homeless people, building capacities of people with disabilities, improving reproductive health of youth, improving health outcomes for transgender persons, and increasing supports for families of children with disabilities.<sup>32</sup> Researchers have labeled their work as “participatory research,” “mutual inquiry,” “community-based action research,” “empowerment research,” and “participatory action research.” As Minkler<sup>31</sup> points out, the term participatory action research has been used increasingly as an overarching term for research that emphasizes dialogue between researchers and consumers, meaningful participation of the consumers, and commitment to education and social change.

Because PAR literature is very broad, we focus on applications of PAR only in the field of disability and rehabilitation. The National Institute on Disability and Rehabilitation Research (NIDRR) has been promoting the concept of PAR for more than a decade. In 1991, William Graves, former director of NIDRR, introduced PAR and wrote that the goal of using this approach was better science and better practice.<sup>33</sup> The amendments to the Rehabilitation Act of 1992 encouraged NIDRR to focus on scientifically sound research that is responsive to the needs of the consumers.<sup>34</sup> In 1993, NIDRR proposed a policy statement on constituency-oriented research and dissemination, which reflects PAR principles.<sup>35</sup> In April 1995, the conference “Forging Collaborative Partnerships in the Study of Disability—A NIDRR Conference on Participatory Action Research” was held. Since then, more researchers in the disability and rehabilitation field have been embracing the PAR approach.<sup>1,6</sup>

### KEY IMPLEMENTATION ELEMENTS

Several key implementation elements could facilitate the application of PAR. Following the example of Redmon et al.,<sup>36</sup> we examined the disability-related PAR literature for strategies on how to incorporate this approach into the research process. We also relied on Danley and Ellison’s handbook<sup>37</sup> for participatory action researchers. Four elements of implementation have been identified: (1) participant selection and recruitment, (2) role and relationship clarification for researchers and participants, (3) research team education, and (4) management and support. We will describe the importance of each element and will recommend specific activities for its implementation. To illustrate our points, we will cite exemplars of how scientists have incorporated PAR into their research.

#### Participant Selection and Recruitment

How participants are recruited and selected are essential because subject participation is a core PAR principle.<sup>1,14,22,38</sup> Danley and Ellison<sup>37</sup> have identified personal investment and motivation as the best predictors of sustained participation in a research project. Representative participants who have an investment in or are beneficiaries of the results of research should be chosen. Recruitment of these participants will increase the likelihood of engaging in relevant research activities and obtaining credible, valid, and applied outcomes.<sup>10,39,40</sup>

Activities recommended for implementing the recruitment process include (1) identifying potential team members, (2) advertising PAR opportunities, (3) gaining entry into a setting or a group, (4) developing participatory relationships, (5) orienting potential team members, (6) recruiting team members, and (7) retaining team members. Although these activities may seem linear, the research process determines their actual order. Some activities may occur simultaneously. Also, these activities will have an interactive relationship during the research process.

Before we discuss each activity, we would like to point out that many authors who write about participant involvement use a variety of labels for participants. In this article, we use the terms *consumer*, *participant*, *stakeholder*, *constituent*, and *team member* interchangeably. These labels might not reflect adequately the relationship of the participants to their roles. For example, the label “consumer” may not be well suited for, or welcomed by, somebody who is not a service user. Therefore, in the spirit of PAR, researchers should decide with their collaborators what label would be most appropriate for participants.

**Identifying potential team members.** Fenton et al.<sup>35</sup> have reported that any person or entity who is an ultimate or intermediate beneficiary of a research project should be regarded as a potential PAR team member. Similarly, Fawcett et al.<sup>41(p27)</sup> wrote, “we select a population whose issues and problems are of current or emerging interest to clients themselves, researchers, and society.” Groups of these individuals are often called “relevant constituencies”<sup>35(p1)</sup> or “stakeholders,”<sup>42(p279)</sup> and their composition depends on the project application. Guba and Lincoln<sup>43</sup> have presented 3 categories of stakeholders for inclusion: “agents” of the proposed program (ie, program planners, funders, managers, staff); “beneficiaries” of the proposed program (ie, members of the community who are likely to be positively impacted by the program or its outcomes); and “victims” of the proposed program (ie, members of the community who are likely to be negatively impacted by the program or its outcomes). Although Guba and Lincoln referred to those categories of stakeholders in the context of evaluation research, the same categories can be used in projects with different foci.

Time, money, and interest make it unlikely that all individuals affected by the proposed project will be able to participate; however, it is imperative that all stakeholder groups be represented.<sup>44</sup> Researchers should compose their PAR group with attention to diversity among the constituencies as it relates to power and authority in the program, philosophic orientation, political agenda, and demographic markers (eg, race, class, gender, age).<sup>42</sup> Doe and Whyte<sup>45</sup> have emphasized the importance of collaborating with participants who have varied disability-related experiences. Doe and Whyte have noted that researchers sometimes are inclined to include people with disabilities who are easier to accommodate and whose contributions will maximize the efficiency and expediency of the project. However, if a project is genuinely participatory, efforts should be made to incorporate feedback from participants with less “convenient” disabilities.<sup>45(p25)</sup> Stevens and Folchman,<sup>46</sup> for example, have discussed strategies for inclusion of people with severe developmental disabilities, and Kavin et al.<sup>47</sup> have examined collaborating with persons who are deaf. Naturally, the extent of participant diversity will be dictated by the research question. If the research question is specific to a certain group, members of this group should be predominantly represented. If the research question is general, then participant diversity in terms of type of disability and cultural background should be sought because it may result in more accurate representation.<sup>48</sup>

A broad range of participants is beneficial to the project because it can increase social validation of the project’s goals, procedures, and outcomes<sup>7,8,49</sup> and result in development of a wider range of resources, information, and perspectives.<sup>50</sup> Working with a variety of collaborators presents a challenge because it increases the complexity of research planning and makes establishing common ground more difficult.<sup>39</sup> Turnbull et al.<sup>9</sup> have reported that involving a wide range of stakeholders might result in “drowning” the voices of the primary stake-

holders (eg, parents of children with disabilities) who are outnumbered by secondary stakeholders (eg, teachers, administrators).

An example of potential constituencies for a project designed to increase women's access to local physical activity centers might include women; representatives from local recreation, health, and social service groups; fitness center directors; university instructors and researchers; and funding agencies.<sup>51</sup> As another example, a project focusing on reducing secondary conditions (eg, pressure ulcers, deconditioning, weight gain) for people with spinal cord injuries might include persons with physical disabilities who have secondary conditions, their family members or caretakers, researchers, clinical educators, product developers, rehabilitation engineers, service providers, policymakers, advocate leaders, independent living experts, and representatives of public and private health programs that serve people with disabilities.<sup>6,40</sup>

**Advertising PAR opportunities.** Researchers should consider advertising the proposed project to identified potential constituencies to assure the broadest possible team member representation.<sup>37</sup> The announcements should include a brief description of the project, reasons for inviting participation, general requirements for team membership, potential benefits of involvement, and a scheduled time and place for attending a project orientation session. One approach for attracting potential team members is to develop and distribute a brochure with a perforated, removable reply card that potential members can use to indicate their interest in involvement or to request more information.<sup>37</sup>

Danley and Ellison<sup>37</sup> used this advertising strategy when they investigated the career paths of people with psychiatric disabilities. The authors designed a frequently asked questions (FAQ) sheet to help potential team members decide whether they were willing and able to participate on the PAR team. This FAQ sheet answered the following questions, among others: "What is the PAR process? Why is PAR used for this study? What does it mean to be a research team member? What special competencies will I need? How will I benefit from this experience? How will others benefit from my participation? How much time will I need to allow to participate as a research team member?"<sup>37(p8)</sup>

**Gaining entry into a setting or a group.** Another aspect of implementing PAR is the development of partnership and collaboration among team members, some of whom might be community members and belong to local groups and organizations.<sup>52</sup> The first step in starting a positive relationship with potential collaborators is to approach them in a manner that shows mutual respect and equality and not "experimental colonialism."<sup>53</sup> If the research project is to be conducted in an organizational setting, the researchers may start establishing linkages with an organization by identifying informants who can explain local traditions and philosophy and introduce the research staff to gatekeepers—persons who control access to the organization or setting.<sup>41</sup> Before approaching an organization, researchers should familiarize themselves with its formal structure, clients, goals, policies, and programs.<sup>44</sup> Researchers can develop a stronger connection to the organization by participating in activities that are not associated with the research project, such as the organization's board meetings. To summarize, informants can lead to gatekeepers, gatekeepers to local leaders, and local leaders to potential collaborators. Research staff is more likely to obtain the participation necessary to conduct the proposed project by using a collaborative approach when gaining entry.<sup>1</sup>

Several authors<sup>1,54</sup> have suggested that the participatory manner to approaching potential collaborators is multifaceted,

time-consuming, and demanding. Despite those barriers, it should not be neglected, because it will eventually establish the basis for collaborating in project planning and building trust among the stakeholders.<sup>55</sup> The fact that participatory research is costly in terms of time and resources and yet appears to increase the value of research presents a dilemma for funded research.<sup>56</sup> Typically, the budget allocations do not include expenses for PAR activities, nor do they account for the time needed to develop partnerships. Researchers might experience competing contingencies from the funding agency and from the project itself. One solution to this problem is to provide the funding agencies with evidence of the effectiveness of PAR so they are more likely to provide additional funds for conducting PAR activities.

There are few explicit descriptions of the entry process in the reviewed literature. Balcazar et al<sup>57</sup> have offered an example of gaining entry into a consumer-directed organization serving people with disabilities. They examined the effects of training advisory committee members to identify and report advocacy issues. At the beginning of the project, one of the researchers was a member of the Center for Independent Living (CIL) board of directors. During a board meeting, he reported that the Research and Training Center on Independent Living (RTC/IL), where he worked, was developing materials to assist with advocacy issues. After his announcement, a consumer group's chairperson, who was also on the CIL board, approached him with interest. She asked for assistance in teaching the advisory committee members how to identify and report advocacy issues. She also invited the researchers to meet with the advisory committee. At that meeting, the researchers talked about the advocacy materials developed at RTC/IL and explained the project and its participatory character in detail.

**Developing participatory relationships.** McTaggart<sup>19</sup> has commented that participatory research is a group activity involving "value-based partnership," as defined by Nelson et al.<sup>58</sup> It is, according to Stringer,<sup>44(p160)</sup> "a search for understanding in the company of friends [italics added]." Turnbull and Turnbull<sup>59(p1)</sup> have described PAR as a "collegial model" of interaction among researchers, individuals with disabilities, and their family members. Researchers are beginning to appreciate the role of such partnerships. They directly impact the quality of the stakeholders' experiences and, ultimately, the quality of their enterprise.<sup>44</sup> Specifically, partnerships heighten commitment of all parties, intensify collaboration, and bring more meaningful results.<sup>60</sup>

What is involved in a participatory or collaborative relationship or a value-based partnership? Such partnerships are based on mutual trust and respect, so that members can communicate openly.<sup>54</sup> Ultimately, the goal of such relationships is to develop a nonhierarchical partnership that acknowledges the strengths and perspectives of all the parties.<sup>20</sup>

Factors that facilitate participatory or collaborative relationships include taking part in informal events, meetings, or activities; being on a first-name basis; and celebrating each others' birthdays.<sup>44,52</sup> Stringer<sup>44</sup> has noted that researchers should establish a demeanor that is perceived as legitimate and nonthreatening by all stakeholder groups. They should be aware of their dress, appearance, and language so they do not create a stark contrast between themselves and consumers. For example, Frisby et al<sup>51</sup> have described a situation in which low-income women participants became more comfortable and open with physical activity instructors when the instructors shared personal life experiences with them and facilitated information sharing. The women also commented that the instructors were more approachable because they "looked like

[us] (eg, they did not have perfect bodies and did not wear the latest fashions.”<sup>51(p22)</sup>

Although the strategies for building a productive PAR relationship seem reasonable, accomplishing this goal is difficult because of many historical, practical, and methodologic obstacles.<sup>56,61,62</sup> Blurring boundaries between researchers and consumers is one of those obstacles.<sup>63,64</sup> Eliminating the detachment, which was historically maintained by researchers, may be perceived as resulting in biased and unscientific research.<sup>65</sup> Nevertheless, the criticism that PAR contributes to less scientifically rigorous research is not substantiated.<sup>9</sup> As Graves,<sup>33</sup> Campbell et al,<sup>16</sup> and many others have asserted, if PAR is integrated into a well-designed study, the result will be a well-designed participatory study. Conversely, if PAR is used in a poorly designed study, the result will be a participatory study that lacks methodologic rigor.

Within the PAR approach, researchers must still guard against the threats to validity, reliability, and replication.<sup>66</sup> To ensure validity (internal, external) and replicability, researchers should consider: the use of the most feasible, yet appropriate, experimental designs; the use of instruments that are valid, reliable, technologic, and gather information empirically; detailed descriptions of the dependent and independent variables; documentation of the methods used; the use of reliability assessments for dependent and independent variables; the use of standard procedures for instrument development; the use of appropriate statistical analyses; the use of appropriate procedures for ensuring credibility and trustworthiness of qualitative information; and the use of multiple sources of data and triangulation of those data.

**Orienting potential team members.** Danley and Ellison<sup>37</sup> have described the orientation process as presenting a concrete image of the expectations and benefits to each person so he/she can decide whether to become involved in the project. The expectations can be included in a job description for each position on the team. At this point, this description should be general because a more specific role or relationship will be clarified later in the PAR process. Initially, potential participants should be presented with information on anticipated requirements and benefits. One benefit should be financial compensation for participants' time and effort. Turnbull et al,<sup>9(p186)</sup> for example have explained that paying participants for their time is “critically important.” They have noted that 1 possibility is to incorporate PAR stipends into research budgets. Sometimes, however, participants might decline receiving money for their involvement because of Social Security restrictions. Turnbull has suggested alternative compensation strategies, such as providing vouchers to stores where participants could buy needed items. Also, participants often cannot afford to wait to be reimbursed for expenses. Researchers should consider advanced payment for for time and travel. Potential participants should also be informed of other supports that might make it possible for them to be involved in research (eg, childcare, transportation).<sup>58</sup>

Individual meetings are a preferred medium for project orientation, but a small group format can be used. The orientation meeting should acquaint prospective members with the typical structure and content of future meetings. A staff member should discuss the fact that research meetings will involve dialogue among participants and that the meetings will serve as problem-solving forums. The orientation process could include a research activity exercise (eg, reviewing a data sheet) to increase the interest of the potential participants in the project. The orientation meeting should approximate the duration of a usual research meeting. This will give potential participants an

actual experience as to the time commitment required for involvement.

**Recruiting team members.** Recruiting entails obtaining commitment from a future team member to be a full participant in the project. Individual meetings help encourage discussion about questions and concerns specific to the situation of each future participant.<sup>37</sup> The literature shows very few explicit descriptions of how participants are recruited, but Chataway<sup>67</sup> and Krogh<sup>68</sup> have reported that a written agreement can be used during recruitment to make sure that all parties are presented with the same information. Chataway<sup>67(p751)</sup> has identified this agreement as a “research contract” and Krogh<sup>68</sup> as a Partnership Agreement Framework (PAF). Both authors have suggested that by the time a person chooses to participate in a project, he/she should clearly understand the researchers' intentions and the expectations for participants.

**Retaining team members.** Retention of team members is very important in maintaining consistency throughout the PAR process. At least 3 issues seem to play a role in retaining team members. First, the project should be genuinely participatory. McTaggart<sup>69</sup> has emphasized that authentic collaboration involves consumers in all stages of the research process. If participants notice that they are only included in selected research activities, that they receive little recognition for their work, that their presence in the project is because of political or funding reasons, and all of it is in the guise of participation, they will likely view such practices as tokenism or window dressing and leave.<sup>70</sup> Fenton et al<sup>35(p11)</sup> have recognized that tokenism will alienate constituencies instead of empowering them.

The second issue is that of consumer burnout. If the same individuals are asked to take part in multiple projects or on 1 project in multiple roles, they might feel increased stress and pressure. Although this might not be an issue at the beginning of a project, these problems should be resolved before they occur. The issue of accessibility is also important in retention. If people are asked to participate in a research project, but information is not provided in accessible formats and through alternative modes of communication (eg, use of Braille or sign language) to accommodate their needs, they are more likely to leave. Additionally, the research team meeting times and places have to be accessible in terms of physical, temporal, and financial arrangements. Krogh<sup>68</sup> has suggested that PAR researchers have an ethical obligation to ensure that such arrangements are made, or it is very likely that the participants will not continue their involvement.

### Role and Relationship Clarification

Clarification of roles that the researchers and consumers will play in the research process and of the nature of their relationship to each other are important for several reasons. First, role clarification is a key facilitator in partnership development.<sup>53,71</sup> Second, many researchers have reported that formalization of rules, roles, and procedures is necessary for successful implementation and maintenance of collaborative activities.<sup>68,72,73</sup> Formalization will help structure team makeup and interactions. Third, as Huygens<sup>74,75</sup> has asserted, clear rules and procedures might be a mechanism for ensuring the accountability of professionals to consumers and consumers to professionals. Finally, role or relationship clarification helps eliminate historical preconception regarding differential responsibilities of the team members, minimizes confusion concerning performance expectations,<sup>37</sup> and provides information on how decisions will be made.<sup>9</sup>

To clarify the roles or relationships, it is necessary to define the scope of PAR, member roles, member responsibilities, and how power will be shared.

**Defining the scope of PAR.** The extent, feasibility, and practicality of the roles of team members must be defined. Greenwood et al.,<sup>22</sup> Hall,<sup>76</sup> Sample,<sup>77</sup> and others have argued that full participation is not possible in every situation, and that the scope of PAR will vary depending on the nature of the problem; the knowledge, skills, and experiences of the participants; the environmental context; the aims and capacities of the research team; and the skills of the researchers.

Campbell et al.<sup>78</sup> have discussed 4 research models with different levels of consumer control in PAR. These include user-sensitive research, user- or consumer-centered research, consumer-driven research, and consumer-controlled research. Consumers' roles vary from restricted involvement, to high involvement with moderate power sharing, to full participation and control of the research process. Researchers' roles vary from being "experts" who consult with a consumer-advisory committee, to being collaborators and coinvestigators who still retain final authority on making decisions (often due to relationship with funding agencies), to being members of the team that collectively shares power over decision making and available resources.

Turnbull et al.<sup>9</sup> have discussed a continuum of participation in their research focusing on parents of children with disabilities. According to their continuum, 3 of 6 levels reflect PAR. In those 3 levels, the families' roles changed from being "ongoing advisers" to "coresearchers" to "research leaders."<sup>9(p182)</sup> They noted that PAR should not be implemented based on a "recipe" but should be shaped by the researchers' and the participants' experiences in harmony with project goals. In summary, the first step to clarification of roles and responsibilities is to define the extent of participation that is practical for all the parties involved in the research process.

**Defining member roles.** Turnbull and Turnbull<sup>79</sup> have explained that the PAR process allows researchers and consumers to develop new roles and relationships. Feighery and Rogers<sup>80</sup> have suggested that these new roles should be clarified as soon as the project begins. The scope and the goals of the research will dictate different roles for researchers and consumers. In any project stressing consumer and researcher collaboration, PAR should override the traditional paradigm for conducting research. When applying PAR, researchers should be viewed less as experts, professionals, and principal investigators, and more as consultants, facilitators, and coaches. Consumers, on the other hand, should be viewed less as subjects and more as team members, participants, collaborators, and coresearchers.<sup>6,24,39,53</sup> Whyte et al.<sup>81</sup> and Rains and Ray<sup>82</sup> have noted that the researcher should act more like a coach in team building and a facilitator of mutual learning who also has the responsibility of guarding against violations of research rigor.

Krogh<sup>68</sup> proposed a guide—the PAF—to help researchers accomplish meaningful consumer-researcher collaboration. She identified 7 issues that are relevant to the PAR process and, within each issue, several questions to guide the team in developing a partnership. One of the issues pertains to roles that will be assumed by consumers and researchers. The associated questions are "Have differing contributions and sources of expertise been accomplished? Have the roles been made clear for all partners during each phase of the research? Have the partners identified special conditions for participation to support them in their roles (e.g., access and reduced jargon)? Are roles consistent with the guiding principles and model of collaboration selected for the project?"<sup>68(p32)</sup> She further suggested that PAF can help consumers and researchers in agree-

ing what the new roles will be, what they entail, and how to assume them. Krogh<sup>83</sup> has also stated that defining member roles is a complex process because of the limiting effects of the social construction of disability<sup>84,85</sup> and the belief system embraced by some people with disabilities. Interactions within partnerships can be influenced negatively if researchers emphasize impairments of consumers and/or if consumers perceive themselves as incapable of addressing disability-related issues.

**Identifying member responsibilities.** Identifying responsibility focuses on specifying the demands of each role played by team members and helps build more successful collaborations.<sup>37</sup> Specifications of responsibilities will also help shape behaviors that are consistent with the goals of the research team. Finally, once responsibilities have been identified, their descriptions might help team members discover their own learning, accommodation, and support needs.

Krogh<sup>68</sup> has identified responsibilities as 1 of the 7 areas in the PAF. Some of the guiding questions associated with assigning responsibilities are "Has a clear set of responsibilities been determined for each partner? Do these responsibilities support the project objectives and the guiding principles? Have responsibilities been assigned to ensure that the project leads to increased community and academic knowledge? Have the responsibilities to the funder been acknowledged? Have responsibilities to the academic institution been acknowledged?"<sup>68(p32)</sup> The responsibilities should be described clearly in formal job descriptions or they can be agreed on informally during team meetings. Danley and Ellison<sup>37</sup> have also recommended that the responsibilities be communicated in as many media as possible. That is, in a written form, orally by describing the task in an individual or group discussion, or by modeling the task during a meeting.

Danley and Ellison<sup>37</sup> have provided an example of how they identified researchers' responsibilities in their project at the beginning of a study and on an ongoing basis. Some of the responsibilities that were selected, defined, and "matched" with particular member's skills were supervising project activities (principal investigator); overseeing research activities (research director); overseeing day-to-day operations of the project (project director); organizing team meetings and providing instruction and support to the team members (research team coordinator); providing input in the design, development, and implementation of the research; participating in decision making and providing insider's expertise (research team members); providing technical support and assisting with collecting and analyzing data (research assistant); and providing administrative support for the team members (PAR organizer).

Santelli et al.<sup>60</sup> have described responsibilities undertaken by researchers and by consumers—parents of children with disabilities. The researchers agreed to provide information about research design and methods, to lead the development of instruments used in the study, to manage the implementation of measurement, to run all the statistical analyses and summarize the data, and to publish the findings in professional journals. The consumers, on the other hand, agreed to provide information about a Parent-to-Parent organization, to suggest modification to the research design and methods so that the study would be more "comfortable for parents,"<sup>60(p220)</sup> to recruit participants, and to write about the findings in a way that would be clearly understood by other parents.

Finally, Whitney-Thomas<sup>25</sup> has discussed identifying responsibilities as an activity during PAR process. There are several tasks in which researchers primarily are engaged, several tasks in which consumers primarily are engaged, and several tasks in which researchers and consumers have shared

responsibility. Researchers usually encourage team members to identify problems and to search for solutions. They also share their expertise in research methods, develop data systems, conduct data collection, and lead data analysis. Consumers identify and prioritize needs and concerns and provide technical assistance to develop data systems, to conduct and participate in data collection, and to participate in data analyses according to skills and interests. Researchers and consumers collaboratively select research questions, decide on data collection and research design, determine data utilization, disseminate information, and develop action steps for future inquiry.

The previously described examples show a range of responsibilities that consumers and researchers might undertake, but the common element is, as Santelli et al<sup>86</sup> have suggested, the emphasis on the responsibilities being "selected by" rather than "assigned to" each PAR team member based on their skills and preferences.

**Sharing of power.** According to McTaggart,<sup>69</sup> authentic participation means "sharing in the way research is conceptualized, practiced, and brought to bear on the life-world"; this connotes shared power over resources, decisions, actions, events, and activities.<sup>44</sup> Historically, there has been a power imbalance between researchers and research participants.<sup>87</sup> In the traditional research paradigm, researchers act as experts who exert professional control by assuming high-status positions, by taking responsibility for higher-level decisions, and by questioning the participants' ability to make decisions.<sup>40,53,88,89</sup> Consumers, on the other hand, are excluded from decision making—they do not have "voice and choice."<sup>90</sup>

In contrast, PAR research strives to diminish the inequality in power by encouraging the researchers to step down and share control, and the consumers to step up and take more control.<sup>58</sup> This shift in power can be facilitated by several actions. Nelson et al<sup>58</sup> have recommended that "de-powering" of dominant groups can be accomplished by rotating leadership responsibilities; by creating horizontal, not hierarchical, structures within the research team; by encouraging substantial involvement of representatives of traditionally underrepresented groups; by providing tangible supports so that barriers to participation are minimized; and by training and hiring consumers. Nelson et al<sup>91</sup> have also listed activities that might reduce the power differences between researchers and stakeholders. They are having consumers chair committees, setting a tone of informality, using vernacular language, and encouraging member to contribute to discussions regarding the direction and the process of the research. Constantino and Nelson<sup>92</sup> have recommended that participants be involved in the decision-making process regarding policy, planning, and service delivery issues. Involvement in making decisions, as a strategy for diminishing power imbalance, is also emphasized by Turnbull et al.<sup>9</sup>

Despite the fact that many actions can be undertaken to narrow the gap between control held by professionals and by consumers, several authors<sup>52,67,93</sup> have stated that it might not be possible to close that gap completely. As Church<sup>93</sup> has recommended, professionals and consumers should engage in the previously mentioned activities to approximate equality to the highest degree feasible.

### Educating the Research Team

One of the objectives of PAR is decentralization of knowledge<sup>94-96</sup> so that knowledge is not the private property of an elite group, but is shared by the team members. The goal of PAR is to reduce or eliminate the gap between the outsiders (researchers) and insiders (collaborators), and between research and practice. Decentralization of knowledge can be

achieved by educating both researchers and consumers on a number of dimensions.<sup>95</sup> This education occurs throughout the research process when researchers and participants are challenged constantly by ideas, information, and arguments posed by other members of the team.<sup>81</sup> The assumption is that each member of the research team has different areas of expertise. However, although obtaining access to this diversity of provinces of knowledge is a core element of PAR, it sometimes can create conflict among stakeholders. To prevent such friction, education of the team members is needed.<sup>37</sup> Such education will enhance individual and team performance,<sup>37</sup> increase the ethics of the research process,<sup>20</sup> contribute to decentralization of knowledge,<sup>97</sup> and affect stakeholders level of empowerment.<sup>41</sup>

Activities recommended for educating the research team include (1) addressing learning needs of the researchers, (2) understanding learning needs of the consumers, and (3) structuring learning opportunities. Danley and Ellison<sup>37</sup> have recommended that to accomplish these 3 activities, all team members should put forth an assumption that ignorance is inherent in all stakeholders and that everybody will have to learn new skills.

**Addressing learning needs of the researchers.** Nelson et al<sup>58</sup> have emphasized the need for education and consciousness-raising for professionals about the realities that the consumers have faced and continue to face as well as about the social dynamics between the dominant and subordinate groups. Similarly, Turnbull et al<sup>98</sup> have noted that the researchers should invest time and effort in understanding the context and realities of each of their partners. Santelli et al<sup>60</sup> have stated that this understanding will come from sharing expertise, perspectives, and skills with the consumers.

Researchers also might need to learn how to increase the ecologic validity of research, how to improve interaction between theory and practice, and how to achieve flexibility in the choice of methods and professional inquiry.<sup>99</sup> Nyden and Wiewel<sup>100</sup> have suggested that researchers should learn to do more interdisciplinary work—to collaborate with researchers from different fields and with the consumers. Fenton et al<sup>35</sup> also recommended that researchers be trained specifically in conducting participatory research. Some of the skills involved in participatory or collaborative work include ability to work as a team, to communicate with a variety of individuals, to express difficult content in lay person's language, and to facilitate group activities.

The ability to communicate with consumers using everyday language has been emphasized by several researchers.<sup>9,101</sup> Professionals' use of jargon has been described as a major impediment to the participatory process because it supports the alienating and dominating relationship between the researchers and the participants in the form of "language control."<sup>4,87,102,103</sup> In contrast, content that is presented in easy-to-understand fashion facilitates participation by stimulating ideas, discussions, and overall responsiveness of consumers to researchers.<sup>44,104</sup> In summary, the researchers may have to learn about the partners in the research process, to do interdisciplinary work, and to translate scientific information into lay person's language.

**Addressing learning needs of the consumers.** Fenton<sup>35</sup> reported that NIDRR supports training persons with disabilities and their families so that they can participate meaningfully in the research process. Several authors<sup>16,24,92,100,105</sup> have asserted that consumers should learn the basics of scientific method and the mechanism of conducting well-designed studies so that they can understand research, carry on dialogue with researchers and other professionals, and conduct research themselves.

Consumers need the skills or capacity to participate effectively in partnerships and to be perceived as legitimate partners.<sup>106</sup> Consumers may have to learn to express opinions publicly and improve advocacy skills,<sup>6,105</sup> to identify problematic issues, to plan and conduct actions, to evaluate outcomes,<sup>54</sup> to conduct and lead group activities,<sup>53</sup> to recognize that adverse conditions are a function of social, political, and economic context,<sup>3</sup> and to reinforce researchers who engage in PAR.<sup>99</sup>

**Structuring learning opportunities.** Danley and Ellison<sup>37(p17)</sup> have defined structured learning as “arranging chances for all the team members to acquire new knowledge and skills.” Usually, these opportunities are spread throughout the research process and their content corresponds to the research activity at hand, but some training might take place in the initial stages of the project or even before the project begins. For example, the tenets of PAR could be taught at the universities, long before the researchers start a collaborative project.<sup>74,106</sup> Additionally, conferences devoted to PAR should be organized, conference proceedings should be written and published, and effective means of dissemination of the information should be used.<sup>35</sup> Again, for some researchers and consumers, this could take place before any specific PAR project begins. During a PAR-influenced project, learning opportunities for researchers and consumers can be arranged through handouts, didactic presentations, workshops, hands-on experiences, and, most important, dialogue.<sup>37</sup>

In summary, in PAR, there is an assumption that all the team members have individual provinces of knowledge, but that they also need to acquire new skills. Training researchers and consumers will increase the number of skills they develop, making the participatory process more meaningful. Additionally, training will decentralize knowledge and empower consumers.

## Management and Support

Determining and fulfilling management and support needs are an important element of the research process because they can result in effective and efficient completion of tasks. Danley and Ellison<sup>37</sup> pointed out that the integrity of the project calls for structuring team activities in a way that honors PAR philosophy but also facilitates achievement of the intended research outcomes. Stringer<sup>44</sup> has also recommended that management and support activities be well organized so that the coherence and purpose of the research process is maintained across all stages of the project.

Activities recommended for implementing the management and support process include determining management needs, determining support needs, and assigning responsibilities and resources.

**Determining management needs.** Management activities are procedures that provide control and direction.<sup>37</sup> They include establishing meeting times and places; preparing an agenda for meetings; creating, organizing, preparing for, and implementing group activities; selecting a group decision-making method (eg, majority rule vs consensus building) and conflict resolution method; and creating resources and payment mechanisms for compensating and reimbursing team members.

A plan of operations should be developed that clarifies tasks, responsibilities, and time lines for management activities. The plan will differ among projects, but the commonality should be participant involvement in the discussion, creation, and approval of these procedures. Sometimes, however, these procedures have to be developed in the early planning stages of the project, before the constituencies become involved. In this case, the procedure should be reexamined and modified based on the feedback from the consumers once the project begins.

Regarding a decision-making process, Turnbull et al<sup>9</sup> have suggested identifying which issues are in the realm of researchers' expertise and have the researchers make recommendations on those issues that collaborators may endorse. Likewise, issues lying primarily within the expertise of the collaborators should be recommended by the collaborators to the researchers for endorsement. The underlying principle is acknowledgment of the diverse contributions that all partners bring to the research process. Additionally, when conflicts occur, negotiation and compromise should drive the conflict resolution process.

**Determining support needs.** Support activities are procedures that strengthen and sustain team member participation.<sup>37</sup> They include: providing basic logistical and clerical assistance (eg, typing and copying materials, recording minutes), accommodating individual disability needs (eg, providing assistance with reading the materials, providing tapes of sessions to members who could not attend), arranging for “coaching sessions” for consumers who are not comfortable with participation in group activities, and providing a forum for the professionals to discuss challenging issues associated with the PAR process.

**Assigning responsibilities and resources.** Assigning responsibilities and resources refers to specifying accountability and allocating project assets (a portion of the project's budget) so that the logistics can be effectively applied. This activity should also be a part of the process of clarifying roles and relationships.

In summary, PAR-influenced research, as any other research project, needs to be conducted efficiently and effectively. However, because effective implementation is highly demanding in time and fiscal resources,<sup>107</sup> there is a need to determine and implement management and support needs that would ensure cohesion of the project's goals and the PAR philosophy. Once such needs are determined, responsibilities and resources should be allocated to apply those procedures as designed.

## CONCLUSIONS

Many authors<sup>1,9,10,60</sup> have asserted that the PAR approach has substantial benefits. These advantages are said to result in better science and better practice. Moreover, they relate well to the concept of social validity.<sup>8,108</sup> This article has described a systematic approach to implementing PAR in the field of disability and rehabilitation. We have shown that PAR, as an element of the research process, has been mostly described in anecdotal and qualitative reports. Future research needs to empirically address the *net value* of PAR. Randomized case control studies should be conducted that objectively assess the effectiveness and contribution of PAR to disability studies. Suggested dependent variables for this research might include the acceptability of the research goals, procedures, and outcomes to study participants (or those likely to benefit from it) and the magnitude of positive effects for PAR-enhanced research versus non-PAR-enhanced research. Assessments should be made as to whether the research has a wider dissemination and utilization under research conditions influenced by PAR compared with standard conditions. Other variables of interest could include the cost effectiveness of time and resources needed to complete PAR-enhanced research. These future studies will provide evidence of PAR's effectiveness and information about conditions under which PAR is most effective.

Specific studies should also address the best approach for using PAR with different types of research. For example, survey research may require a different approach than community-based intervention or single-subject design research. Scientists should consider documenting the procedures they use

for PAR in various research designs and approaches so that others can test for generality and replicability. Such studies will help inform the field of disability research as to whether PAR should be a philosophic orientation to conducting research or part of an actual methodology that could be incorporated into research procedures.

From a clinical viewpoint, lessons learned from the PAR process should be adopted and adapted to allow greater patient involvement in the rehabilitation process. Instead of PAR, we suggest participatory action treatment (PAT). Clinicians could analyze whether PAT would help patients achieve better outcomes at hospital or rehabilitation center discharge. Given medical cost containment and shortened length of stays, alternative treatment approaches, such as PAT, should be compared with standard treatment protocols. Such comparisons would allow determining whether more positive clinical outcomes, such as reduced secondary conditions or return visits to the emergency department, are associated with PAT.

PAR is an approach that appears to increase the value of research to benefit both researchers and consumers. Its empirical value remains untested under various settings, research designs, and populations. As disability researchers systematically test PAR and evaluate its effects, they can contribute to the development of a more rigorous and relevant research process.

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